Evaluation of the impact of a hospice at home service on place of death

Thesis

Evaluation of the impact of a hospice at home service on place of death

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Preface

The thesis is all my own work. It utilises data collected as part of an evaluation of the Cambridge Hospital at Home for palliative care, for which I was responsible. I was responsible for all aspects of the study design and its execution. All data were collected and encoded by me, with the exception of a proportion of the NHS electronic record data used, which were collected by a computer assistant under my supervision (as indicated within the text of the thesis). I performed all the quantitative and qualitative analysis reported and wrote the thesis in its entirety.

Four papers have been published using material from this thesis:

Grande GE, Addington-Hall JM and Todd CJ (1998) Place of death and access to home care services: are certain patient groups at a disadvantage? *Soc Sci Med*; **47** (5): 565-579.

Grande GE, Todd CJ, Barclay SIG and Farquhar MC (1999). Does hospital at home for palliative care facilitate home death? a randomised controlled trial. *BMJ*; **319**: 1472-1475.

Grande GE, Todd CJ, Barclay SIG and Farquhar MC (2000). A randomised controlled trial of a hospital at home service for the terminally ill. *Palliat Med;* **14** (5): 375-385

Grande GE and Todd CJ (2000). Why are trials in palliative care so difficult? *Palliat Med*; **14** (1): 69-74.

The thesis is 81,000 words long (including references and appendices).

Abstract

Fewer patients are able to die at home than would wish to do so. A literature review showed that palliative home care patients are more likely to die at home than others. However, findings may be due to case mix differences, as variables which are positively associated with home death, are also positively associated with access to palliative home care. The thesis investigated the impact of a hospice at home (HAH) service on place of death.

An observational, case control study compared 121 patients referred to HAH with 206 patients not referred. Multivariate logistic regression analysis showed that HAH care was strongly positively associated with home death. However, case mix effects could not be discounted.

A randomised controlled trial (RCT) compared 186 patients allocated to HAH care with 43 controls. Analysis was intention to treat. Intervention patients were not significantly more likely to die at home than control patients (67% versus 58%).

The RCT suffered loss of power and dilution of the treatment effect. Post hoc multivariate logistic regression analysis showed a positive association between actual HAH input and home death. However, this association was no stronger than that between less intensive home care services and home death. Concerns about case mix effects remained.

Content analysis of professional and family carers' explanations of endstage inpatient admissions for RCT patients suggested such admissions were mainly perceived to result from factors unrelated to insufficient home care. While some patients may have benefited from added home support, this may not have affected place of death.

Additional home care introduced on top of good existing provision, among patients who are already likely to die at home, may have little impact on home deaths. Careful consideration of service aims, target group, other health service context is required before introduction of further hospice at home services.

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Dedication

Til papsen

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CHAPTER 1: INTRODUCTION AND LITERATURE REVIEW

1.1 OUTLINE OF THESIS

The central aim of this thesis is to investigate whether introduction of hospice at home can lead to an increase in home deaths. To address this aim I will review the literature to assess whether past research suggests that added home care is likely to increase home deaths; investigate the impact of a local hospice at home service on the number of home deaths within the service catchment area; and assess the contribution of other local home care services towards death at home.

The literature review will investigate demographic and clinical variables associated with home death, and consider whether added palliative home care is likely to have any impact on these variables. It will furthermore assess existing evidence that palliative home care services have increased the number of deaths at home. Finally, the review will consider the demographic and clinical characteristics of home care patients, to assess whether case mix differences may account for any associations between home care and home death.

The investigation into the impact of a local hospice at home service on place of death will take the form of a case control study and a randomised controlled trial (RCT). Post hoc analyses of the RCT data will be performed to further consider the potential contribution of hospice at home and other local home care services to home death.

In the case control study, place of death will be compared for patients referred to the local hospice at home service versus a similar sample of cancer patients not referred. A comparison between the two groups on demographic, clinical and other service variables will enable identification of potential confounding variables and help identify characteristics of the hospice at home patients. Multivariate logistic regression analysis will be employed to investigate the association between the hospice at home service and home

death, and to control for potential confounding effects of all identified case mix differences between the two groups.

Subsequently an RCT, using intention to treat analysis, will investigate the impact of the local hospice at home service on home deaths. Patients referred to hospice at home will be randomised to hospice at home and standard care or a control condition of standard care only. It is assumed that the procedure of randomisation will distribute any confounding variables equally between groups, therefore cancelling out any effect they may have on outcome.

Due to the dilution of treatment effect which often occurs in palliative care trials (McWhinney et al, 1994), a post hoc multivariate logistic regression analysis will be conducted on the RCT sample, to investigate the association between actual hospice at home input and home death among patient referred to hospice at home. It will also control for and consider the association between other local home care services and home death. Any other potentially confounding variables will be controlled for.

Finally, a post hoc content analysis will be conducted of reasons for inpatient deaths within the RCT sample, as reported by those involved in the patient's care. This is a change in analysis from aggregate level to the level of the individual, and considers whether, in the individual case, inability to die at home was attributed to insufficient home care, or to factors on which home care may have had little or no impact. This tentatively seeks to assess whether there are limits to what hospice at home and other home care may achieve, given the difficulties associated with terminal care at home.

1.2 OUTLINE OF CHAPTER 1

This chapter will address why death at home is of importance, and why it may be desirable to increase the proportion of people dying at home. A brief overview of the history of palliative care is provided. Next, a literature review is presented which seeks to establish the factors associated with death at home, whether palliative home care is likely to have an impact on home deaths, and whether it is possible to dissociate the

effects of home care from those of case mix. A subsequent section will describe the local hospice at home service, its context and the ways in which it differs from home care evaluated in past research. Finally, a more detailed outline of the studies forming the basis for the thesis and the chapter contents will be provided.

1.3 WHY DEATH AT HOME IS OF IMPORTANCE

Research suggests that fewer patients are able to die at home than would wish to do so. In England and Wales in 1995, 21% of deaths from all causes and 26% of death from cancer occurred in people's own homes (ONS, 1997). Even lower percentages have been cited for cancer deaths in USA and Australia (Hunt and McCaul, 1996). However, research indicates that death at home is preferred by one half or more of terminally ill patients (Dunlop et al, 1989,Townsend et al, 1990, Karlsen and Addington-Hall, 1998, Carroll, 1998, Pritchard et al, 1998, Lee and Pang, 1998), by a majority of the general public (Charlton, 1991, Toscani et al 1991, Ashby and Wakefield, 1993) and by primary care professionals (Cartwright, 1991). Studies have also shown that bereaved informal carers are more likely to state that the place of death was right (Ward, 1987, Addington-Hall et al, 1991) and suffer less distress (Catalan-Fernandez et al, 1991) if the patient died at home rather than in hospital. However, Seale and Cartwright's (1994) report that the proportion of carers who would have preferred death to occur elsewhere was the same for patients who died at home as for patients who died in inpatient care (hospital and hospice), and Addington-Hall and Karlsen (2000) found more psychological distress among carers of cancer patients who had died at home compared to deaths elsewhere.

Expressed preference for home death depends on the patient's situation and the proximity to death. Townsend et al (1990) found that while 58% of 59 terminally ill cancer patients would have liked to die at home given their existing circumstances, 67% would have liked to do so given ideal circumstances. A study in Singapore (Lee and Pang, 1998) found that while 52% of 44 hospitalised cancer patients would have liked to die at home, an additional five would have liked to do so if their symptoms could be adequately controlled, and six had there been domiciliary support available. Furthermore, while 35 (45%) of 77 relatives in the study preferred terminal home care, an additional 12 would have considered looking after the patient at home had they been able to have

home care support. Hinton (1994a) conducted a longitudinal study of 77 hospice home care patients and their carers and asked them where the patient should be, given their present condition. There was a decrease in preference for home care from nearly 100% at the beginning of the study to 54% of patients and 45% of relatives in the final week before death. Nevertheless, the percentage preferring home care remained higher than the percentage of patients currently dying at home.

There is therefore an apparent discrepancy between the current level of death at home and what patients, carers, health professionals and the public want. Past research investigating post hoc reasons for hospital admissions suggests that a large proportion of end of life admissions are due to insufficient home support, professional or informal. Doyle (1980) considered 268 patients under the care of a palliative home care team, and reported that 90% of hospital admissions were due to stress on relatives, the impossibility of providing more nursing staff, the lack of night sitters or the absence of equipment. However, the actual data on admissions were not presented. Wilkes (1984) investigated a random sample of 262 adult deaths of all diagnoses (2:1 hospital to home deaths) in a UK city. The main reasons for hospital admission, according to bereaved relatives, were that better care was available in hospital (41%) and that relatives were physically unable to cope (26%) or psychologically unable to cope (19%). Herd (1990) reviewed 157 consecutive adult deaths from malignant disease in a semi-rural area. A reason for admission could be obtained from a hospital doctor or patient notes for 55 of 74 inpatient deaths. Problems with informal support was implicated in many cases; lack of informal carer (22%) or the carer becoming unable to provide care (45%). However, symptom control was also mentioned for 55% of patients. Lubin (1992) reviewed the hospital charts of 96 palliative care patients admitted to a Canadian university hospital, and reports that caregiver burden was mentioned as a reason for admission in 24% of cases. The remaining reasons mainly related to symptom control. Dunlop et al (1989) considered 100 patients supported by a hospital terminal support team. This study found that 28 patients remained in hospital until death reportedly because the carer was unable to cope with home care, the remainder due to deterioration during their stay or death while awaiting transfer. It therefore appears that for a considerable proportion of patients inpatient death is attributed to a lack of professional support, or to a lack of, or problems with, informal support which may be ameliorated through increased professional support.

In summary, past research indicates that fewer patients are able to die at home than would wish to do so. Inpatient deaths are in many cases perceived to result from insufficient home support and the burden on informal carers. It is therefore often assumed that palliative home support should increase patients' likelihood of dying at home, if they so wish. However, so far there has been little research to establish the actual impact of such palliative home services on place of death.

For simplicity death at home is consistently treated as the desirable outcome in the analysis for this thesis. In practice it has to be recognised that this not always what patients and carers want, an issue which is revisited in the Discussion. However, as the focus of the thesis concerns how the proportion of home deaths may be increased, given that many patients who wish to die at home fail to do so, the present analysis implicitly treats home death as the desired outcome.

1.4 BRIEF HISTORY OF MODERN PALLIATIVE CARE SERVICES

The vast majority of papers reviewed are from the UK, the US and Australia, and some background is provided to the palliative care in these countries.

In the UK the Marie Curie Foundation began a day and night home service for cancer patients following a survey of patients in 1952 (Higginson, 1997). Marie Curie nurses provide hands-on nursing care by staff experienced in palliative care. The first modern hospice is considered to be St Christopher's Hospice in Sydenham, founded by Dame Cicely Saunders' in 1967 (Siebold, 1992), although hospices like St Joseph's hospice in Hackney existed before then. During the 1970s specialist palliative services mainly took the form of inpatient hospices. Lunt and Hillier (1981) report that there were 58 inpatient units, 32 home care teams and eight hospital support teams in Britain 1980. However, in 1980 a working group on terminal care ("The Wilkes report") advised that emphasis should rather be placed on providing support, education and training for hospital and community staff who in practice provide the bulk of care for the terminally ill. They suggested that this support could be provided by palliative support teams in hospitals and the community (Wilkes, 1980).

A substantial increase in the number of home support teams followed, their number eventually overtaking the number of inpatient hospices. Such teams provide specialist input in the form of advice and training, while physical care is provided by relatives or other services. Specialist nurses normally form the core of the team. These are mainly Macmillan nurses, i.e. nurses initially funded by the Cancer Relief Macmillan Fund. Doctors and social workers are often available for advice or may form additional members of the team. Other support such as physiotherapy, occupational therapy or a chaplain may be provided (Higginson, 1997). By 1996 there were 377 palliative home care teams registered in the UK (Hospice Information Service, 1996), the majority of these were advisory home support teams. However, some hospice at home services were also beginning to emerge. These may provide 24 hour nursing or night sitting. In addition to the palliative home care teams Marie Curie nursing services now operate in all counties in England (except Isle of Man), and in Scotland, Wales and Northern Ireland (Hospice Information Service, 1996). The UK studies reported in the literature review consider home care in the form of advisory palliative support teams rather than hands-on palliative care.

Palliative care proponents in the US were inspired by Dame Cicely Saunder's work in the UK in the 1960s. The first hospice home care program began in 1974. In the US palliative care began either in the form of home care services, some of which later acquired beds, or support teams in hospitals. Hospice was viewed more as a concept of care than a place. From the early 1980s hospices were predominantly home hospice programs, some of which may be affiliated with hospitals, and what few hospice inpatient facilities there were largely disappeared. By 1990 there were an estimated 1450 hospice programmes in the US. With few exceptions their home care is only provided for patients who have a primary carer. Programmes normally consist of multidisciplinary teams, with some exceptions in rural areas. Depending on the type of programme, support can range from hands-on care to counselling only (Siebold, 1992).

Australian palliative care services provide a combination of inpatient and domiciliary care (Komesaroff et al, 1989, Bradshaw, 1993, Hunt and McCaul, 1996). In South Australia, where the majority of reviewed studies were conducted, only one inpatient hospice existed in 1981. However, by 1990 there were four inpatient

hospice units and outreach palliative services which covered metropolitan Adelaide (containing 70% of the South Australian population). In addition there were eight palliative care programmes serving rural areas. In 1990 56% of cancer deaths in South Australia had some hospice involvement. South Australian palliative care is based on a multidisciplinary team which supervises care in hospital, inpatient hospice units and patient homes (Hunt and McCaul, 1996). Thus their model of palliative home care is similar to that of the UK advisory home support teams. By 1987 Perth in Western Australia had a palliative domiciliary service, a cottage hospice and a palliative care unit within an acute general hospital (Bradshaw, 1993). At about the same time Melbourne had an inpatient hospice and a palliative home care programme (Komesaroff et al, 1989).

1.5 LITERATURE REVIEW

The present literature review seeks to summarise present knowledge regarding variables associated with death at home compared with death elsewhere, and to assess whether improved home care is likely to have an impact. It furthermore reviews any evidence available that introduction of palliative home care has increased the number of patients dying at home. Finally, it considers the case mix of patients referred to palliative home care to assess whether the case mix of home care patients can account for any association between home care and death at home.

1.5.1 Literature identification and inclusion criteria

The review considers research relating to home deaths and home care for adults. Studies were identified through the databases Medline Express 1968-2000/02, SERLINE on SilverPlatter 1999, PsychLIT 1887-1999, and by manually following up references cited in identified papers. The search terms used were "place of death" or "location of death", and "terminal home care", "palliative home care", "terminal domiciliary care" or "palliative domiciliary care". The review was limited to English language papers, and therefore mainly contains research conducted in the UK, USA and Australia. However, papers from Canada, Italy, Sweden, Norway, Israel and Switzerland are included. The results therefore relate to the historico-cultural

context of Europe, North America and Australia in recent decades, a context in which the ideas of the hospice movement have taken root and palliative home care has begun to develop (Siebold, 1992, Hunt et al, 1991). One cannot assume that results can be generalised outside this context as dying may take a different form and meaning in other cultures. The resources and organisation of care are also likely to differ considerably.

The review excludes studies conducted on patients identified through hospital specialist oncology services as these patients probably represent a selective subset of the cancer population, the particular characteristics of which are difficult to determine. Only 40% of cancer patients in England and Wales see a specialist oncologist (Association of Cancer Physicians, 1994). This review furthermore excludes studies investigating place of death for patients already under palliative home care. These patients also represent a selective subsample, the characteristics of which we seek to establish in this chapter. The demographic and clinical factors associated with home death for this particular patient group have been reviewed elsewhere (Grande et al, 1998). All other studies which consider patient or carer variables associated with death at home or referral to home care were included, regardless of study methodology. Furthermore, the review includes the seminal study on Life Before Death by Cartwright et al (1973) and its follow up study twenty years later (Seale and Cartwright, 1994).

Death at home is compared to other care settings overall, but data relating to differences in proportions of deaths in different inpatient settings are not considered. The review of characteristics of home care patients contains studies in which either inpatients or the remaining patient population form the comparison group. Summary tables are provided in Appendix 1. These tables include all variables investigated in the studies relating to home death and home care, and their findings are reported in this chapter. The tables furthermore describe the setting, participants and design of each study, but these are not repeated in the text unless they may account for differences in findings between studies.

1.5.2 Variables associated with death at home

This section seeks to establish which variables are associated with death at home, and whether these variables suggest that improved home support will have an effect on home death.

First studies investigating place of death of patients of all diagnoses are reported, and second, studies investigating place of death of cancer patients only. Seale and Cartwright (1994) note that cancer patients are different from other disease groups. They tend to die at a younger age and are therefore more likely to have a living spouse and other living relatives. Age related symptoms such as mental confusion and disability are less common. Furthermore, the incidence, duration, intensity and type of symptoms follow a different course, and a terminal phase can be more easily distinguished. Data from the Office of National Statistics show that cancer patients overall are slightly more likely to die at home than the population as a whole (ONS, 1997). The variables related to place of death for cancer patients may therefore be different to those for the rest of the population, and it was therefore considered important to consider cancer separately where possible. The data relating to place of death are presented first, followed by a discussion of whether variables relating to home death are likely to be amenable to home support.

- Studies investigating place of death for patients of all diagnoses

Fifteen studies were identified between 1973 and 1994 (Table 1.1, Appendix 1). These studies show the importance of informal carer support in facilitating home deaths. Patients who lived with someone, were married or had a partner were more likely to die at home than those who did not (Cartwright et al, 1973, Hunt et al, 1991, Clifford et al, 1991, Seale and Cartwright, 1994). Only one study found that divorced patients were more likely to die at home than others (Polissar et al, 1987). Two early studies suggest that the identity of the informal carer appeared to matter. If the wife was the carer, death at home was more likely than if the husband was the carer (Bowling and Cartwright, 1982). The availability of children for support appeared more important than the presence of a spouse, and the presence of daughters more important than that of sons (Cartwright et al, 1973).

Polissar et al (1987), Clifford et al (1991), Seale and Cartwright (1994) and Brock and Foley (1998) found that patients aged 75 years and above were less likely to die at home than other adults. Cartwright et al's (1973) earlier study found home deaths to be least likely for patients under 45 years of age and patients aged 85 and above. Hunt et al (1991) found no relationship between age and home deaths in Australia in the time period 1910 to 1987. The negative relationship between old age and death at home may therefore be a relatively recent phenomenon, possibly one which has emerged following substantial decreases in the proportion of patients dying at home in recent decades (Hunt et al, 1991, Seale and Cartwright, 1994).

Men were more likely to die at home than women (Cartwright et al, 1973, Bowling and Cartwright, 1982, Rosenberg and Short, 1983, Polissar et al, 1987, Hunt et al, 1989, Hunt et al, 1991, Clifford et al, 1991, Seale and Cartwright, 1994, Brock and Foley, 1998).

Numerous studies suggested that social class was not related with home deaths when considering patients of all diagnoses (Cartwright et al, 1973, Polissar et al, 1987, Hunt et al, 1991, Clifford et al, 1991, Seale and Cartwright, 1994).

According to data from the 1960s, patients with fewer restrictions and a shorter care period were more likely to die at home than their counterparts, while length of incontinence rather than incontinence per se was associated with hospital deaths (Cartwright et al, 1973). Patients who died in hospital were more likely to have suffered pain and confusion, while home death was associated with vomiting, loss of appetite, bedsores and dyspnoea (Cartwright et al, 1973).

Home deaths were least likely for patients who died from cerebrovascular disease (Cartwright et al, 1973, Polissar et al, 1987), pneumonia and influenza (Bowling and Cartwright, 1982, Polissar et al, 1987), which are often associated with old age. Home deaths were most likely for those with heart and other vascular disease (Cartwright et al, 1973, Bowling and Cartwright, 1982, Polissar et al, 1987, Clifford et al, 1991), which often imply a sudden death. Cartwright et al's (1973) data suggest that patients with respiratory disease were among

those least likely to die at home, while Bowling and Cartwright (1982) report that patients with bronchitis were among those most likely. Although these two disease categories overlap they are not the same. Hunt et al's (1991) findings indicate that home death was less likely for cancer patients than for non-cancer patients in Australia during the 20th century.

Patients who died in hospital were more likely to have spent time in hospital in the last year of life than patients dying at home (Bowling and Cartwright, 1982), while those who died at home had greater district nurse input (Cartwright et al, 1973). However, level of primary or secondary care input may have been an effect of place of death itself.

Finally, Seale et al (1997) found that death at home was more likely when both patient and carer knew that the patient was dying and were positive towards openness, than when the patient was unaware of prognosis. Such open awareness was more prevalent among patients in social class I and II, and among cancer patients compared with other diagnoses.

- Studies investigating cancer patients' place of death

Sixteen studies were identified between 1978 and 2000 (Appendix 1, Table 1.2). These studies again indicate that being married was positively associated with death at home, either for both sexes (Moinpour and Polissar, 1989, Costantini et al, 1993, Jordhøy et al, 2000) or, as found in Australia, for males only (Roder et al, 1987, Hunt et al, 1989). Home death was positively related to number of children for both sexes (Hunt et al, 1989) and with access to informal help in general (Jordhøy et al, 2000). Axelsson and Christensen (1996) found no effect of marriage on home deaths. However, their study was limited only to specific diagnostic groups and the number of home deaths was small (n=24).

Moinpour and Polissar (1989), Hunt et al (1989), Hunt et al (1993), Karlson and Addington-Hall (1998), Higginson et al (1998, 1999) and Jordhøy et al (2000) all report that older patients were less likely to die at home than younger patients. However, an Italian study by Costantini et al (1993) found that it was the older

patients who were most likely to die at home. Similarly to the studies of all diagnostic groups in the previous section, an early study did not find any effect of age (McCusker, 1983). Neither did the small scale study by Axelsson and Christensen (1996) which considered only specific cancer diagnoses.

English, Australian and Norwegian studies found that women were less likely to die at home than men (Roder et al, 1987, Hunt et al, 1989, Hunt et al, 1993, Higginson et al, 1998, 1999, Jordhøy et al, 2000). Karlsen and Addington-Hall (1998) found a similar trend, but this failed to reach significance. However, Costantini et al(1993) found that Italian women were more likely to die at home than Italian men. Two small scale studies failed to find an effect of sex which may be associated with their size and different design (Parkes, 1978, Axelsson and Christensen, 1996). Parkes (1978) home group included approximately 25% of patients who spent most of their time at home but eventually died in hospital. As noted, Axelsson and Christensen (1996) only included specific diagnostic groups. However, a large scale US study also failed to find an effect of gender on home death (McCusker, 1983).

Cancer patients who had higher education (Costantini et al, 1993) or were living in a higher socioeconomic area of residence (McCusker, 1983, Roder et al, 1987, Hunt et al, 1993, Higginson et al, 1994, Higginson et al, 1999) had a greater likelihood of dying at home than their counterparts. McCusker's (1983) US study showed this trend to be reversed only for people in areas sufficiently deprived to warrant reimbursement of home care services. While Higginson et al (1994) investigated both patients with cancer and those with circulatory disorders, socioeconomic differences were found for cancer patients only. A recent study (Sims et al, 1997) suggests that those in skilled occupations were more likely to die at home compared both to higher and lower occupational groups. However, the lower occupational groups, representing 61% of the sample, were considerably more likely to die in hospital and less likely to die in a hospice compared with the other groups. Thus the lower groups appeared at a disadvantage both in terms of home death and access to cancer related services. Karlsen and Addington-Hall (1998) found that among patients who wished to die at home according to bereaved carers, those in non-manual occupations were most likely to die so, although they found no significant relationship between social class and home death overall. Jordhøy et al's (2000) data suggests that higher status accommodation may be associated with home death, but this relationship was not significant

(p=0.06). In contrast, Johnson and Oliver (1991) reported that the district in their investigation was more disadvantaged than surrounding districts, yet had a higher proportion of home deaths. However, they did not conduct a formal investigation of this relationship. Parkes (1978) found no effect of social class. Overall, however, there appears to be an association between socioeconomic status and home death for cancer patients, while no such relationship was found when considering patients of all diagnoses.

Patients who were diagnosed less than a month before death were less likely to die at home (McCusker, 1983, Polissar et al, 1987, Moinpour and Polissar, 1989, Axelsson and Christensen, 1996). This may reflect a high incidence of hospital tests and attempts at treatment in the month following cancer diagnosis. Increase in interval between diagnosis and death beyond a month appeared to have little effect on home deaths.

Parkes' (1978) data suggest that patients who died in hospital were less mobile, more likely to suffer confusion and more likely to suffer pain initially than patients remaining at home. However, in the final phase of illness, patients who remained at home were likely to experience more pain. A more recent study by Karlsen and Addington-Hall (1998) found that reports of good pain control in the home was associated with home death. They also found that patients who had needed Social Services help with shopping, cooking and transport were less likely to die at home. Such support may reflect lack of an informal carer or longer term disability.

Diagnoses associated with home deaths were colorectal cancer (McCusker, 1983, Higginson et al, 1998), cancers of the GI tract in general (Clifford et al, 1991, Hunt et al, 1993, Higginson et al, 1999), genitourinary cancers (McCusker, 1983, Johnson and Oliver, 1991, Costantini et al, 1993) and cancers of the bone or connective tissue (Higginson et al, 1998). Patients with haematological cancers were more likely to die in acute care (McCusker, 1983, Polissar et al, 1987, Roder et al, 1987, Costantini et al, 1993, Hunt et al, 1993, Higginson et al, 1998), presumably because this diagnosis is normally associated with ongoing hospital treatment and contact (Hunt and McCaul, 1998). Higginson et al (1998) found that patients with head/neck or lung cancer were more likely to die at home, while Costantini et al (1993) found the reverse. Patients with breast cancer (Higginson et al, 1998) and primary cerebral tumours (Johnson and Oliver, 1991) were less likely

to die at home. Breast cancer may be associated with women's reduced likelihood of dying at home (Roder et al, 1987, Hunt et al, 1989, Hunt et al, 1993, Higginson et al, 1998), while cerebral tumours may be associated with confusion, a variable increasing likelihood of hospital death (Cartwright et al, 1973).

Karlsen and Addington-Hall (1998) found that reportedly "poor" GP care and having inpatient stays were negatively associated with death at home. However, having community or palliative home care nursing, special equipment or attendance allowance support was positively associated with home death. In contrast, Jordhøy et al (2000) found that having conventional home care at trial entry decreased likelihood of patients dying at home. It is difficult to assess what form of home care this was and whether the measure may be associated with length of care dependency. Finally, Karlsen and Addington-Hall (1998) found that patients whose relatives reported a preference for home death were more likely to die at home than those who did not.

- Summary of variables associated with home death and discussion of the likely impact of home care

Past research has consistently shown that there is an association between the support available in the home and home death, thus additional home care may be likely to increase the number of people dying at home. If the patient has a partner, spouse, children or otherwise someone living with them, death at home is more likely. Input from district nursing or palliative home nursing and "good" GP care are also positively associated with death at home. For the nursing care, however, it is difficult to assess whether nursing input made home death more likely or whether home death increased likelihood of receiving nursing input.

Patients aged 65 or older are less likely to die at home than younger patients. This may be because old age is associated with complex and long standing care needs which require inpatient or institutional care. However, old age is also associated with fewer informal care resources in the home due to a greater likelihood of living alone or having a carer who is frail and elderly. The only study which found that older patients were most likely to die at home, was Italian. This suggests that it is not age per se but the patient's societal, cultural and family context which determines place of death (Costantini et al, 1993). This may explain why early Australian, UK, or US studies failed to find a clear age effect, as family structures would have undergone considerable changes

in these countries in recent decades. Seale and Cartwright (1994) note an increase in the proportion of elderly (>65) living alone from 10% in 1945 to 34% in 1980. Moinpour and Polissar (1989) found that once patients in the US received specialist palliative care, patients over 84 were more likely to die at home than other adult age groups. UK studies have found no relationship between age and place of death once patients receive palliative home care (Dunphy and Amesbury, 1990, Hinton ,1994b). The disadvantage of old age in relation to home death may therefore to a large extent be due to lack of home support. Thus added home support may benefit older patients.

Men are more likely to die at home than women. Only one large scale study in New York State found that men and women with cancer were equally likely to die at home (McCusker, 1983). However, other large US studies from the same period, incorporating patients of all diagnoses, did find men more likely to die at home than women (Rosenberg and Short, 1983, Polissar et al, 1987, Brock and Foley, 1998). These were conducted in different states to the McCusker (1983) study, and circumstances surrounding place of death may have varied with geographical location. However, gender differences in home death otherwise seem to be consistent across the English speaking world, whether studying all diagnoses or cancer only. As women on average live longer than men, some of the differences may be attributable to variables associated with old age. Women are more likely to be frail by the time they die and are considerably more likely to live alone in old age than men (Seale and Cartwright, 1994). Correspondingly they have a greater likelihood of dying in nursing or residential homes than men (Cartwright et al, 1973, Polissar et al, 1987, Hunt et al, 1989, Hunt et al, 1991, Clifford et al, 1991, Seale and Cartwright, 1994). However, our review also showed that home death was more likely when wives and daughters were the carers rather than husbands and sons, and that the benefits of being married in some settings only apply to men. Thus gender roles may play a part, and home support may be less adequate for women than men, even if there is a primary carer present. Only one study in Italy found women to be more likely to die at home than men, something its authors attributed to the preservation of the extended family structure (Costantini et al, 1993). It is unlikely that differences in findings between this study and the rest can be attributed to study design as the methods employed were very similar (Appendix 1, Table 1.2). The studies which suggested that men were less effective carers than women are now quite old (Cartwright et al, 1973, Bowling and Cartwright, 1982). Gender roles may by now have begun to change, but gender differences in

home death persist. Whether women are less likely to die at home because they often live alone or because they still have less effective informal care, an increase in home support should help increase their likelihood of dying at home.

Results relating to informal care, age and sex are similar for patients in general and cancer patients in particular. However, only cancer patients showed an association between socio-economic status and home death. This was found even when cancer and non-cancer patients were investigated separately within the same study (Higginson et al, 1994). One explanation that socioeconomic differences are only found for cancer patients, is that a greater range of support is available for cancer than for other diseases, e.g. in the form of Marie Curie nursing care in the UK or hospice care (Addington Hall, 1998). This may maximise differences between those who are most able to gain access to services versus those who are less able. Only Parkes (1978) found no effect of socioeconomic status on home death for cancer patients, but this study took place while palliative care services in the UK were still in their infancy. McCusker's (1983) finding that socioeconomic differences in place of death in the US disappeared in areas sufficiently deprived to warrant reimbursement for home services, suggests the difference was related to home care access. Within the UK income in itself should not affect ability to access palliative care services. However, high socioeconomic groups may be better able to pay for additional care, have homes more suited to home care and live in areas with better service provision (Tudor-Hart, 1971). In addition they may be better able to speak to health professionals (and thus gatekeepers) on equal terms. Physicians' consultations vary depending on the socioeconomic status of the patient (Stewart, 1983, Mathews, 1983, Roter et al, 1997, Wiggers and Sanson-Fisher, 1997). Furthermore, while people of all backgrounds may be equally likely to visit a GP, those with a background similar to the doctor may be more likely to be referred on to other professionals (Alberts, 1998). Seale at al (1997) furthermore reported that there was significantly more openness about dying among higher socioeconomic groups, which may make it easier for health professionals to introduce palliative care. Openness is associated with increased likelihood of home death (Hinton, 1994, [home care patients only], Seale et al, 1997). If the socioeconomic differences in cancer home deaths are indeed due to unequal ability to access the range of services available, wholesale introduction of more home support may not increase the number of home deaths, but only increase the help for those who already have adequate support.

Cancer diagnosis within a month of death is negatively associated with home death, possibly because hospital tests and attempts at treatment often follow diagnosis, leaving little remaining time for organisation of home care. However, Moinpour and Polissar (1989) found that if they do access palliative home care, patients who die within one month of diagnosis were more likely to die at home than patients with earlier diagnosis. Thus rapid response home support may help these patients.

Early research showed that greater dependency, confusion and length of care period was associated with death in hospital (Cartwright et al, 1973, Parkes, 1978). These factors are probably associated with caregiver burden and should be as relevant today as they were at the time of the reported studies. To the extent that palliative home support can ease caregiver burden, it may increase likelihood of home death up to a point. Cartwright et al (1973) and Parkes (1978) also found differences in symptoms between home and hospital settings, although it was difficult to assess whether symptom control was cause or effect of setting. Karlsen and Addington-Hall (1998) suggest that good pain control at home was associated with home death. Specialist palliative home care teams should be able to improve symptom control at home (Hearn and Higginson, 1998).

The diseases least likely to be associated with home death may be those normally associated with old age, while diseases which often imply a sudden death were related to death at home. Among cancer patients, greater likelihood of dying in hospital may be associated with repeated hospital contact (haematological cancer), confusion (CNS tumours) or gender differences (breast cancer). While a UK study found that patients with head/neck or lung cancer were more likely to die at home (Higginson et al, 1998), an Italian study found the reverse relationship (Costantini et al, 1993), again raising the possibility that findings are due to cultural and procedural differences rather than characteristics of the terminal disease. The greater likelihood of home death among colorectal cancer patients may be related to the potential of colostomy bags for removing the distress associated with faecal incontinence. It is more difficult to explain why some of the other associations between cancer diagnosis and home death exist. However, it is not diagnosis per se, but the implications it has for caregiver burden and symptom control, which is likely to be associated with death at home. To the extent home

support can ease caregiver burden and maintain adequate symptom control, it should ameliorate the effect of particular diagnoses on home death.

In summary, our present knowledge of factors affecting place of death would imply that the percentage of home deaths might be increased by increased professional home care. This is supported by research on post hoc reasons for hospital admission, in which many hospital admissions are attributed to insufficient support in the home.

1.5.3 Evidence for an association between palliative home care and home death

In accord with the conclusion of the previous section, there is some evidence that palliative home care may increase likelihood of home death. Patients who have palliative home care are more likely to die at home than other patients (Zimmer et al, 1985, Greer et al, 1986, Moinpour and Polissar, 1989, Komesaroff et al, 1989, Dunphy and Amesbury, 1990, Costantini et al, 1993, Sessa et al, 1996, Rosenquist et al, 1999). Home care furthermore reduces the number of days of rehospitalisation (Smeenk et al, 1998). Appendix 1, Table 1.3 shows setting, design, type of home care service considered in each study and the percentage of patients dying at home.

The type of palliative home care appears to matter. Hinton (1996) found an increase in the percentage of home deaths among palliative home care patients following changes in the organisation of the home care service, including allocation of nurses to individual patients and addition of day hospital facilities. Patients receiving home care attached to an inpatient service are considerably less likely to die at home than patients receiving home care not thus attached (Mor and Hiris, 1983, Greer et al, 1986, Ward, 1987, Moinpour and Polissar, 1989, Smith et al, 1992). Data from Greer et al (1986) and Moinpour and Polissar (1989) suggest that hospice home care with bed attachment may still be associated with more deaths at home than conventional care, but not greatly so. Integration with inpatient care may facilitate admission. However, home care services with and without inpatient attachment may also differ in the degree of home support provided.

There is some indication that the introduction of home care in an area has an impact on place of death within the local population. Costantini et al (1993) found an increase in home deaths locally following the introduction of a home care service. Johnson and Oliver (1991) found a transient increase in home death following the introduction of home care, while (Ward, 1987) found a modest decrease following introduction of hospice based home care and a moderate increase following the introduction of home based home care. However, the impact of home care may depend on the other services available in the area. Thorne et al (1994) found that GPs' access to hospice home care had no impact on place of death in areas in which GPs also had access to community beds. GP community beds reduced the likelihood of dying at home.

Nevertheless, these studies do not allow us to conclude that palliative home care causes an increase in home deaths. First, patients referred to home care may be more likely to die at home simply because they are the patients best able to remain at home. Second, a greater input of home care may simply be a function of place of death. That is, patients who die at home are more likely to receive care in this setting. Third, any changes in home deaths in a district following introduction of a service may be due any number of other changes within the district.

Only two randomised controlled trials of home care have been conducted, thus in theory removing effects of case mix (Zimmer et al, 1985, Jordhøy et al, 2000). However, whilst Zimmer et al's (1985) study showed that a larger percentage of the home care group died at home (71%) compared to controls (47%), no significance level was reported. Testing of the data provided suggests the result was not significant. Furthermore, a higher number of the control than intervention group was lost to follow up, and patients who died (n=43) represented only a quarter of the patients randomised (n=167). Jordhøy et al's (2000) study involved cluster randomisation with six clusters, and the intervention group differed significantly from controls on several demographic variables. While multivariate logistic regression analysis did show decreased likelihood of home death in the control group, logistic regression may not guarantee that all confounding variables have been controlled for. Thus concerns about case mix differences remain.

1.5.4 Studies investigating the case mix of palliative home care patients

This section considers more closely whether patients referred to home care appear to possess characteristics which increase their likelihood of dying at home.

Eighteen studies were identified from 1983 to 1999 (Appendix 1, Table 1.4). The studies reviewed compare hospices with home care only versus hospices with beds (which may also provide home care), the home care branch of a hospice versus its inpatient branch, or home care overall versus no home care. These home care alternatives will all be referred to as home care, and section 1.4.3 above showed that patients under such home care were more likely to die at home than their comparison group (also see Appendix 1, Table 1.3). In the US presence of a primary carer is normally a precondition for receiving home care. Thus when considering variables associated with referral to home care below, we distinguish between studies of services which admit both patients with and without a carer and studies of services which only admit patients with a carer, when relevant to the results.

Studies of services admitting patients both with and without a carer found that having a primary carer, being married or living with someone increased the likelihood of being referred to home care (McCusker, 1985, Komesaroff et al, 1989, Dunphy and Amesbury, 1990, Costantini et al, 1993 Bradshaw, 1993). Having a spouse as the primary caregiver also increased likelihood of referral to home care compared to other carers (McCusker, 1985). Studies of services admitting only patients with a primary carer, found that that referral to home care was less likely if the carer did not live with the patient or was employed (Mor and Hiris, 1983, Mor et al, 1985, Greer et al, 1986, Powers and Burger, 1987) or elderly (Mor and Hiris, 1983). Referral to home care was less likely if the carer was male, even when carer employment was considered in the analysis (Mor et al, 1985).

Most studies of services admitting patients both with and without a primary carer indicate that older patients are less likely to be referred to home care (Evans and McCarthy, 1984, McCusker, 1985, Komesaroff et al, 1989, Dunphy and Amesbury, 1990, Costantini et al, 1993, Talmi et al, 1997, Eve et al,

1997) or to hospice care in general (Hunt and McCaul, 1996, 1998). Only Sessa et al (1996) found no age effect. For studies of services admitting only patients with a carer age effects were less clear (Mor et al, 1985, Greer et al, 1986, Powers and Burger, 1987). Mor et al (1985) found no effects of age. Greer et al (1986) and Powers and Burger's (1987) results suggest that patients under 65 years of age were more likely to be referred to conventional care than older patients. However, conventional care patients had the highest study refusal rates, and those who refused were significantly more likely to be old. Therefore the conventional care sample may be younger as an artefact of sample recruitment.

Studies which found a gender effect mostly found that women were more likely to be referred to home care than men (Mor et al, 1985, McCusker and Stoddard, 1987, Dunphy and Amesbury, 1990). However, an Italian study found that women were more likely to be admitted to inpatient hospice care than home care (Costantini et al, 1999). However, most studies report no effect of gender (Evans and McCarthy, 1984, McCusker, 1985, Costantini et al, 1993, Sessa et al, 1996, and Talmi et al, 1997, Eve et al, 1997).

Referral to home care was positively related to professional and non-manual occupations (Komesaroff et al, 1989), higher income (Greer et al, 1986) and higher education (Constantini et al, 1993). Greer et al (1986) found that patients with income below $10,000 were less likely both to be referred to home care or conventional care compared to care in hospice with beds. Tables presented by Mor and Hiris (1983) also suggest that home care patients were more likely to be college educated and have higher family incomes.

Patients with longer survival from diagnosis tended to be referred to home care rather than inpatient care (Greer et al, 1986, Powers, and Burger, 1987, McCusker and Stoddard, 1987, Komesaroff et al, 1989, Dunphy and Amesbury, 1990) and hospice care in general (Hunt and McCaul, 1996, 1998).

Longer contact with the local oncology centre was positively related to referral to home care (Sessa et al, 1996), which could relate to time from diagnosis or to degree of involvement with specialist care. Komesaroff et al (1989) found that patients for whom specific cancer therapy was not appropriate were less likely to receive home care.

Patients referred to home care had a better level of functionality and fewer nursing care requirements than those referred to inpatient care (Mor and Hiris, 1983, Mor et al, 1985, Greer et al, 1986, Powers and Burger, 1987, Bradshaw, 1993). Talmi et al (1997) and Costantini et al (1999) found that patients admitted to home care had longer survival from admission than patients admitted to inpatient care, which may relate to level of functionality upon admission. McCusker (1985) found that patients who used home care compared with those who did not, had a longer terminal care period (over 45 days), defined as a period of progressive malignancy and a switch towards palliative rather than curative treatment.

Patients with haematological malignancy were less likely to receive home care (Evans and McCarthy, 1984, McCusker and Stoddard, 1987, Sessa et al, 1996) or hospice care in general (Hunt and McCaul, 1996, 1998). Likewise home care was less likely for patients with cancers of the central nervous system (CNS) (Dunphy and Amesbury, 1990). Lung cancer was positively associated with home care (Evans and McCarthy, 1984, Dunphy and Amesbury, 1990, Costantini et al, 1993) and this care location was also associated with a greater incidence of dyspnoea (Dunphy and Amesbury, 1990). An American study (McCusker and Stoddard, 1987) and an Italian study (Costantini et al, 1993) found that breast cancer was positively associated with home care, while a UK study (Evans and McCarthy, 1984) and a Swiss study (Sessa et al, 1996) suggest the opposite trend. Among patients with head and neck cancer, oral cavity tumours were negatively associated with home care (Talmi et al, 1997).

Talmi et al (1997) found that pain severity on admission to palliative services was negatively associated with home care. Powers and Burger (1987) report that the patient's appetite change, cold sweats, calmness and happiness, and the carer's stress, time commitment, loss of income, perceived patient burden and happiness were associated with home care. The patient being lonely, apathetic and frightened was associated with other care. However, these factors may have been measured subsequent to admission to care. Powers and Burger (1987) report that patient weight loss was associated with home care while Talmi et al (1997) report the opposite.

Perhaps not surprisingly the patient's care location towards the end was related to home care use. McCusker (1985) found that patients who spent most of their terminal care period at home were more likely to be home care users. Several authors found a negative association between hospital inpatient care and referral to home care (Mor et al, 1985, Greer et al,1986, Gray et al,1987, Sessa et al, 1996).

- Discussion of case mix findings and comparison with variables associated with home death

Many of the factors associated with increased likelihood of referral to palliative home care are similar to the factors related to increased likelihood of home death. Presence of a primary carer (preferably not male, old or employed) increased likelihood of referral to home care. Thus referral to home care may be more likely when there is already good informal support in the home, a factor which is also associated with home death.

Old age was negatively associated both with home care and home death. However, the clearest age effects for home care were found when considering services admitting patients both with and without a primary carer, rather than services admitting only patients with carers. Thus age effects may be associated with the likely presence of a primary carer and with introducing home care where there is already informal support. However, older patients are also less likely to access inpatient hospice and specialist care (Addington-Hall et al, 1998, Turner et al, 1999). Thus there may be discrimination against old age in relation to service access in general, as suggested by Cartwright (1993).

Cancer patients from lower socioeconomic groups were both less likely to die at home and to access palliative home care. As suggested in seciton 1.4.2 this may be related to inability to pay for such services where provision is not free, but may also be associated with poor service provision in deprived areas, poorer ability to negotiate with health professionals and less openness about death.

Other variables negatively associated with both home care and home death were poorer level of functionality and high nursing care requirements, haematological malignancy and CNS tumours. In relation

to the above variables, home care patients are clearly those patients we would expect to die at home anyway.

Other variables show less clear patterns. Two US and UK studies found that women were more likely to access home care than men (McCusker and Stoddard, 1987, Dunphy and Amesbury, 1990). However, studies from this part of the world found that men were the ones most likely to die at home. In contrast, Costantini et al (1999) found that Italian women were more likely to admitted to palliative inpatient care than men, but also more likely to die at home. Whatever the explanation behind these apparently contradictory patterns, the case mix of home care patients as far as gender is concerned, does not appear to be related to any advantage in achieving home death.

Length of survival (beyond one month) was related to referral to home care but not to home death. Longer survival may mean that patients have longer time to establish a relationship with local health care professionals and adjust to the disease. It may therefore make access to home care more likely, while the eventual place of death may be determined by factors other than survival, such as eventual nursing care requirements and length of terminal phase. One should note that one study found that referral to home care was also positively associated with a prolonged terminal care period. However, patients with a short care period are more likely to die at home.

While both UK and Italian studies found lung cancer to be positively associated with home care, a UK study reports that lung cancer patients were more likely to die at home than other diagnoses, while an Italian study reports they were less likely to do so. While breast cancer was negatively associated with home death, results on its association with home death were mixed.

Despite potentially contradictory patterns for some variables, the characteristics of patients referred to home care are overall very similar to those of patients who die at home, particularly in relation to presence of a primary carer, age and socioeconomic status. Palliative home care is clearly not evenly distributed among the terminally ill population. Instead it appears to reach those patients already most likely to die at

home. It is therefore difficult to determine whether home care patients are more likely to die at home because of case mix or the home care itself.

1.5.5 Evidence for effect of case mix versus effect of home care on place of death

Only three studies have attempted to assess the relative contributions of home care as opposed to other variables, using multivariate analysis. Mor and Hiris (1983) found that US hospice patients who died at home were younger, more likely to have a fit primary carer and belong to a high socioeconomic group compared to patients dying as inpatients. However, a discriminant function analysis showed that the variable best able to predict place of death was the type of hospice, i.e. whether it was hospital versus home-care based. Once type of hospice was considered, knowledge of patients' demographic characteristics and support-network added only one percent to the ability to predict site of death. As the differences in case-mix between hospices may account for this finding, the authors also considered the effect of case mix only. Discriminant function analysis showed case-mix could predict place of death correctly in 60% of cases while hospice affiliation predicted place of death correctly in 70% of cases. Mor and Hiris' (1983) study only included hospice patients who died during their hospice stay, thus excluding patients discharged to other care settings. This may have increased the likelihood of finding that patients tended to die in the care setting in which the hospice specialised.

A logistic regression analysis of cancer patients in South Australia (Hunt and McCaul, 1996) showed that place of death was largely determined by whether or not the patient was admitted to a hospice (providing either home or inpatient support). While admitted and non-admitted patients differed on several demographic and clinical variables, multivariate analysis showed that these variables had very little effect on the odds of dying in different settings, once presence or absence of hospice care was considered.

Costantini et al (1993) also used logistic regression to investigate the relative contribution of palliative home care, demographic and clinical variables to place of death. Palliative home care emerged as the strongest predictor, but age and education were also associated with high odds ratios for home death, while sex, marital status and diagnosis made significant contributions to the model.

The above studies showed that when other variables were controlled for, home care made an independent contribution to home death and also the largest contribution compared to other variables. However, while the multivariate analyses can control for known variables, they may be less able to control for the underlying patterns which the variables may represent or for unknown variables. Randomised controlled trials should counter this problem, but the two trials considered in section 1.4.3 either apparently failed to show a significant result (Zimmer, et al 1985) or may have been subject to selection bias (Zimmer, et al 1985, Jordhøy et al, 2000). Thus the question still remains whether palliative home care allows more deaths to occur at home.

1.5.6 Literature review conclusion

There are good reasons to believe that added palliative home care support should increase the number of patients dying at home. The review shows that home death is associated with the level of informal care resources in the home. There are furthermore good reasons to believe that the effect of age and sex on place of death is in part due to their relation with care resources available. The effect of socioeconomic status on home death in cancer patients may be related to ability to access home care. Home care may furthermore ameliorate the effect of clinical variables if such variables are associated with caregiver burden or with symptom control needs susceptible to specialist intervention at home. If late diagnosis reduces time available for organisation of home care, rapid response home support may help. There will always be patients whose care needs, circumstances and preferences render home death impossible. However, the review of variables associated with home death suggests that additional home care should increase the likelihood of death at home for many patients. Studies of the relationship between palliative home care services and home death appear to confirm this, in that a considerably larger percentage of palliative home care patients die at home compared to other patients.

Nevertheless, a concern still remains that the observed association between home care and home death are due to case mix. Studies of the case mix of home care patients suggest that they possess the same

characteristics as the patients who are most likely to die at home in terms of informal support, age, socioeconomic status, functionality, nursing care requirements and some diagnoses. Only for sex and time scale of survival were there differences. Thus overall the patients who receive home care are the patients already most likely to die at home, and this may account for the association between home care and home death.

Two randomised controlled trials reviewed did not fully remove this concern. While studies using multivariate analysis suggested a strong relationship between palliative home care and home death, this type of analysis can only control for known and measured variables. However, the variables identified are probably markers of broader, underlying patterns we do not fully understand. For instance, we suggested that old age may be associated with complexity of care needs, disease pattern, gender and social support structure. Age may also have implications for cultural outlook, interaction with health professionals, home facilities and several other variables, any of which may be important for home death and show a relation with age. Age in itself does not cause home or inpatient death, it is a marker for variables which may only be indirectly controlled for through multivariate analysis. There are furthermore potentially important variables which are not measured at all, for instance the primary carer's attitude towards home death. Multivariate analysis cannot control for the unknown, and among the factors causing place of death there are still many unknowns.

Even if the analysis does include the essential variables, multivariate analysis does not necessarily enable us to assess the relative contribution of variables in a model. If there is close association between home care use and any other variable entered into the multivariate analysis, one variable may mask the effect of the other (Norusis, 1994). This is a concern as the review suggests that home care is indeed associated with other variables one may wish to control for in relation to place of death.

The finding that the case mix of the people who die at home is the same as those who receive home care presents further concerns apart from the purely methodological. Added home care support may well increase the chances of dying at home. However, it may only reach those who are already at an advantage

in relation to home death. Thus, even if home care is beneficial in helping people die at home, selective distribution may render it ineffective in raising the proportion of home deaths, because it only reaches patients for whom additional help makes little difference. A new home care service may therefore only increase home deaths if it is specifically targeted towards patients at a disadvantage in dying at home, or if it is allocated without any influence of patient characteristics as in a randomised controlled trial.

The thesis investigates whether a local palliative home care service increases the number of deaths at home. In doing so it seeks to separate the effects of the case mix of home care patients from the effects of the service itself. A brief description of the local service and its setting is provided below, and the chapter finishes with an outline of the thesis and its approach to the research question.

1.6 THE HOSPICE AT HOME (HAH) SERVICE AND ITS SETTING

The "Cambridge Hospital at Home for palliative care" (HAH) commenced in June 1994. The aims of HAH are to improve provision of care, particularly at night, for the terminally ill and increase choice of place of care for these patients. HAH can provide up to 24 hours nursing care a day in the home for approximately two weeks. The service can normally accommodate two to three patients at a time depending on need. It is available to patients of all diagnoses for terminal care, i.e. when death is anticipated within two weeks. It is also available for respite care for patients with cancer, motor neurone disease and AIDS with palliative needs at any point during their illness. Patients must be aged 16 or above and be resident in the former Cambridge Health District. The patient's GP and district nurse maintain the medical and nursing responsibility for the patient. Referral to HAH implies patient and informal carer preference for home death.

The HAH team initially consisted of four nurses at RGN grade and drew on additional help from Marie Curie nurses and other qualified bank nurses when required. After one year the team was expanded to five nurses at RGN level, two Enrolled Nurses, a Nursing Auxiliary and a HAH coordinator, also at RGN level. Although the team composition varied somewhat over subsequent years, the skill mix and level of staffing

was maintained. All HAH nurses had a specific interest in palliative care and most had Marie Curie nursing experience.

During its first year HAH was coordinated from the Flexible Care office (see below) at the Princess of Wales Hospital in Ely. It later moved to the Brookfield's Hospital site in Cambridge, which is where the Marie Curie Cancer Care office, Arthur Rank House inpatient hospice and the community Macmillan nurses are also located. Although these services shared the same palliative care manager, they were run separately. While there was good communication between HAH and the inpatient hospice, HAH was not a home care service linked to inpatient hospice beds. HAH nurses had informal access to specialist medical advice on the Brookfield's Hospital site.

HAH differs from palliative home care services considered in past research (Appendix 1, Table 1.3). The home care teams assessed in previous studies typically provided symptom control, assessment, advice and training. They were normally multidisciplinary and contained specialist nurses. Although some may have provided 24 hour access, this was for advice or visits. HAH on the other hand provides up to 24 hour hands-on care in the home by nurses who are not specialists, but are experienced in palliative care. HAH nurses therefore resemble Marie Curie nurses, but can provide a higher level of input, and the smaller team may facilitate greater continuity of care (Todd et al, submitted paper). Although HAH cannot provide the more immediate access to a physician, drugs and sophisticated equipment which is possible within inpatient hospice or hospital care, the nursing cover and attention is, if anything, greater than in inpatient settings. HAH should therefore represent the optimum service in enabling patients to remain at home.

1.7 OVERVIEW OF THESIS CHAPTERS

The following chapters consider the role of HAH in particular, and palliative home care in general, in facilitating death at home. The chapters utilise data from an observational (case control) study and a subsequent randomised controlled trial (RCT). As explained in the Preface, these were conducted as part of

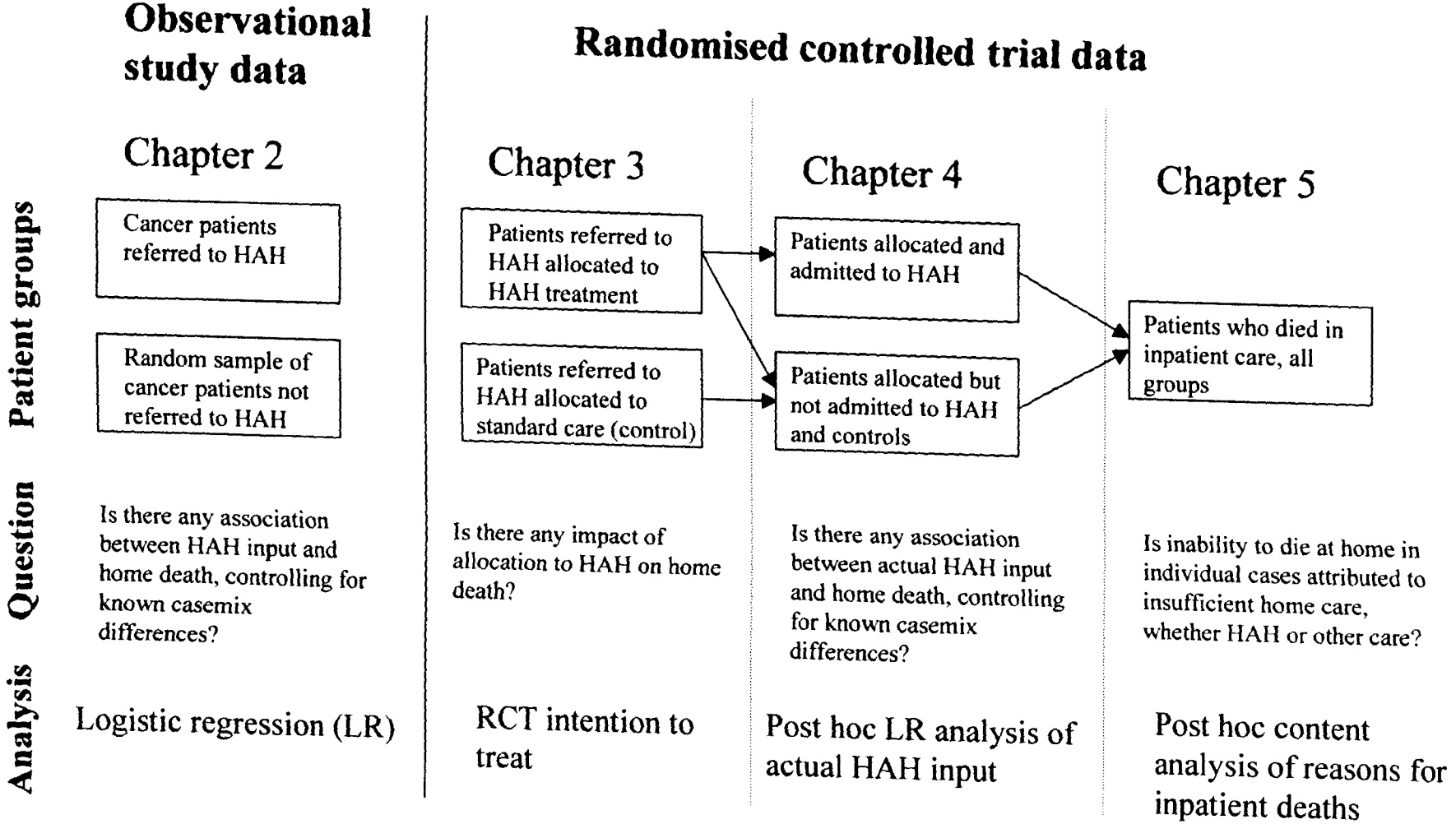
a broader evaluation of HAH. Figure 1 gives an outline of these studies and how the analysis of data from each relate to the thesis chapters. Brief descriptions of chapter contents and rationale are provided below.

- Chapter 2

A retrospective observational study (case control) was conducted comparing number of home deaths among cancer patients referred to HAH with home deaths in a similar, random sample of cancer patients not referred to the service. For each patient data were collected on demographic variables, clinical variables and NHS service input in the last year of life. Univariate analyses were performed to identify case mix differences which may be potential confounders. Variables which differed between groups were subsequently controlled for in a multivariate logistic regression analysis of the relationship between HAH and home death. This study was conducted to establish whether there appeared to be an association between HAH and home death meriting further investigation through an RCT. The approach in this chapter was similar to that adopted by Hunt and McCaul (1996) and Costantini et al (1993). However, the current study represents an improvement on past research. First, it included more variables of potential relevance to home death. Second, it addressed the concerns that HAH care may mask the effect of other, relevant variables, by conducting a separate multivariate analysis of such variables before introducing HAH into the equation. This analysis was not able to fully dissociate the effects of HAH care from those of case mix. It did, however, ascertain whether there was an association between HAH and home death worthy of further investigation. This analysis furthermore served a) to identify the characteristics of patients referred to HAH, which was of importance in our interpretation of subsequent RCT results; b) to illuminate local patterns in relation to place of death and their correspondence with past research.

The focus of the thesis is on HAH in particular, but evidence for association between other home care and place of death was also considered. As is clear from the description of the setting, HAH operates in the context of a range of other home care services, each of which may make its own contribution towards home deaths.

Figure 1: Overview of studies and thesis chapters



- Chapter 3

Because of the limitations of the observational study methodology, the association between HAH and place of death was further investigated using prospective randomised controlled trial (RCT) methodology. Patients referred to HAH were randomised to HAH intervention or a control condition of standard care. This method should ensure that effects of case mix are removed, i.e. randomisation should ensure that any confounding variables are evenly distributed between HAH patients and control patients, and that the service is not, for instance, allocated to those patients already most likely die at home. For each patient data were collected on demographic variables, clinical variables and NHS service input in the last year of life. The HAH and control groups were first compared using univariate analyses to ascertain that there were no significant differences between the groups apart from the intervention itself. The RCT analysis was intention to treat, comparing control and intervention groups regardless of whether the allocated treatment was received or not, thus ensuring that bias was not introduced through the method of analysis (Hollis and Campbell, 1999).

- Chapter 4

Past research has found that a large proportion of patients allocated to palliative care services may fail to receive the intended care (McWhinney et al, 1994). This was also the case for HAH. As many patients allocated to HAH failed to receive the intervention, some doubts remained after the RCT regarding the role of HAH in facilitating home deaths.

Post hoc analyses were therefore performed on the RCT sample to investigate the association between actual HAH treatment and home death. The place of death of RCT patients who received HAH input was compared with place of death of those who did not receive such care. Univariate analyses compared characteristics of patients admitted to HAH with those allocated to the service but not admitted. Any variables which differed between group were controlled for in a subsequent multivariate logistic regression of association between HAH and home death. This approach was similar to that of the first, observational

study. However, in the second study the case mix differences were considerably reduced although not removed.

- Chapter 5

Chapter 5 considered to what extent the inpatient deaths which occurred in the RCT sample may have been attributable to insufficient home care or to variables unrelated to level of home care. It was considered possible that the proportion of home deaths in the RCT sample may represent the limits of what is achievable through added home care, given the considerable difficulties associated with the terminal phase of illness. As part of the HAH evaluation, each patient's GP, district nurse and key informal carer were surveyed about the patient's last two weeks of life, including an open ended question about the perceived reason for any end stage inpatient admission. Content analysis of was used to assess whether the reported reasons for inpatient death among RCT patients were perceived to be directly related to deficiencies in home support, may have been ameliorated by added home support, or in fact rendered the issue of home support unimportant. In contrast to the quantitative analysis, this qualitative analysis gave insight into what happened in each case, according to our respondents. If need for additional home support was considered to be a factor, the analysis furthermore enabled us to consider the type of home support suggested, whether a HAH type service or other forms of home support, e.g. specialist symptom control. While the nature of the data means that the conclusions which can be drawn from this analysis are limited, it nevertheless can inform the concluding discussion of the role of HAH and other home care in home death.

- Chapter 6

The concluding chapter brings together the evidence for the impact of HAH on home death, considers how the service may be changed, the strengths and weaknesses of the study methodology used, the usefulness of place of death as an outcome measure and policy implications.

As the thesis is effect consists of four separate analyses, each chapter will end with a discussion of the results pertaining to that analysis chapter. Only key points from each chapter will be brought forward to the final discussion in Chapter 6.

CHAPTER 2: THE OBSERVATIONAL STUDY

2.1 INTRODUCTION

This chapter first uses univariate analysis to investigate the relationship between Cambridge Hospital at Home (HAH) and home death, and to establish whether there are case mix differences between HAH patients and other patients. Cancer patients referred to HAH are compared with a random sample of patients from the local Cancer Registry who died within the same period. Many patients referred to HAH fail to be admitted, however. A second analysis therefore compares the characteristics of patients who were admitted to HAH care to those referred but not admitted. If variables identified in these two sets of comparisons are also plausibly related to place of death, these variables, rather than HAH, may be responsible for any observed relationship between HAH and home death. Finally, a multivariate logistic regression analysis is performed to investigate the relationship between HAH and home death. All case mix differences identified in the previous univariate analysis are controlled for in the logistic regression.

As shown in Chapter 1, past research enables us to make a number of predictions regarding the demographic and clinical characteristics both of cancer patients referred to palliative home care and of those who die at home. Although HAH is different to palliative home care services investigated in the past, it is plausible that many of the variables associated with referral to such home care also would be related to referral to HAH. There is less comprehensive information available on how patterns of other NHS service provision may relate to referral to home care and death at home.

Chapter 1 showed that in terms of referral to palliative home care, the presence of a primary carer and membership of a high socio-economic group increased likelihood of referral. Being old (i.e. age 65 and above) and having high care requirements reduced the likelihood of palliative home care. Women may be more likely to be referred to home care than men, although the results were not entirely clear. Patients with longer survival from diagnosis tended to be referred to palliative home care rather than inpatient care. Patients admitted to home care furthermore had longer survival from admission than patients admitted to

inpatient care. Patients with haematological, CNS and gastrointestinal cancers were less likely to receive home care, while those with lung, genitourinary and head/neck cancer were more likely to do so. Breast cancer was associated both with home and inpatient care. Several authors found a negative association between hospital inpatient care and referral to home care. Contact with specialist oncology services increased likelihood of home care, especially if this contact was prolonged. Patients who spent most of their terminal care period at home were more likely to be home care users. We would expect to see similar patterns for patients referred to HAH care, compared to patients not referred.

In terms of home death, cancer patients were more likely to die at home if they were male rather than female, young or middle aged rather than old, and if they had a primary carer. Furthermore, cancer patients of high socioeconomic status were more likely to die at home than those of lower socioeconomic status. Survival from diagnosis of less than one month was negatively associated with home death. Patients with haematological, lung, head/neck or CNS cancers were less likely to die at home, while those with genitourinary and gastrointestinal cancers were more likely to die at home. If relationships between these factors and place of death have remained stable in the last two decades, we would expect to observe similar patterns in the analysis conducted for the present study.

Past research has shown a negative association between home death and spending time in hospital during the last year of life and a positive association in relation to community nursing. However, there has been no extensive, detailed investigation into the relationship between services other than palliative home care, and place of death. As well as investigating demographic and clinical variables included in previous studies, the present study will consider in detail the association between all local NHS inpatient and community services and place of death.

HAH co-exists with a range of other local services, each of which may conceivably have an influence on place of death. The district has three Macmillan nurses who provide specialist symptom control and advice. There are also 45-50 Marie Curie nurses who can provide hands-on nursing night or day for up to 20 hours a week. Other community services available are district nursing, night nursing around the city of

Cambridge, Flexible Care nursing coordinated from Ely, north of Cambridge, and other community care, such as physiotherapy and occupational therapy. Flexible Care is a home nursing service similar to Marie Curie cancer care, but funded by the local community trust and available to all diagnostic groups. The district nursing, night nursing, Marie Curie, and Flexible Care services will remain with a patient as long as he/she is considered to require palliative care (defined by the local Marie Curie as death likely to occur within the next six to nine months). Each of these community services may be provided concurrently with HAH care.

The area has a local NHS inpatient hospice with 16 beds. There is also a large acute hospital, Addenbrooke's, with a regional specialist oncology centre. Other NHS inpatient care in the area is provided by a specialist cardio-thoracic centre, Papworth Hospital, and by Lifespan Healthcare NHS Community Trust in the form of continuing care beds, located at the Brookfields, Chesterton, Princess of Wales and Ida Darwin hospitals at the time of the study. There are two private hospitals, the Lea and Evelyn Hospitals. When reporting results, Addenbrooke's Hospital input will be referred to as acute hospital care, Papworth Hospital input as cardio-thoracic specialist care and the Lifespan continuing care beds only as continuing care beds.

2.2 METHODS

2.2.1 Sampling

Cancer patients referred to HAH for palliative care were compared to a random sample of patients from the East Anglian Cancer Registry (EACR). Cancer patients were chosen for analysis because this diagnostic group comprised the vast majority of referrals to HAH (87%), represented a relatively homogenous group compared to non-cancer patients, and because the local Cancer Registry provided an accessible and (nearly) exhaustive sampling frame for the comparison group.

The HAH group comprised patients referred to HAH over a one year period (between 16th June 1994 and 19th June 1995), who were registered on the East Anglian Cancer Registry (EACR) and for whom cancer was recorded as a cause of death. The HAH criteria for referral would furthermore ensure that these patients would be aged 16 or above and be resident within the HAH catchment area, the former Cambridge Health District.

The comparison group was a randomly selected sample of patients who had not been referred to HAH, who were registered on the EACR, for whom cancer was recorded as a cause of death, who were aged 16 or above and resident within the HAH catchment area, and who had died within the same period as the HAH patients. The first step of the selection of the comparison group involved extracting EACR patients resident within the former Cambridge Health District who had died within the designated period, and removing patients referred to HAH. Each remaining EACR patient was allocated a unique number. A random, computer generated set of numbers was then used to identify the EACR patients to be considered for the study. The recorded cause of death was subsequently investigated to identify those patients who had died from their cancer, and who would form the final comparison sample from the EACR. The patient samples will be referred to as the HAH group and CR group respectively.

The sampling strategy means that HAH patients were oversampled relative to the actual proportion of patients referred to HAH within the cancer population (25%). This served to ensure that there were adequate numbers of HAH patients to investigate the association between HAH and place of death.

2.2.2 Selection of variables for investigation

Variables previously identified as relevant to referral to home care and/or to place of death are considered in the study, together with a number of new variables which are likely to be associated with home care or home death.

Variables included which have been identified in past research are age, sex, socioeconomic status (patient's occupation and residential area), and informal support, represented by being married (versus single,

divorced or widowed), having someone living with the patient, and relationship between patient and next of kin. Clinical variables considered are diagnosis and survival since diagnosis (total length of time and diagnosis within a month of death). The thesis will furthermore consider the number of non-cancer causes of death recorded on the death certificate. Whilst not directly related to referral to home care, this variable has previously been found to be associated with referral to specialist palliative care in the form of hospice care (Seale and Cartwright, 1994). Contact with specialist oncology services is also included.

In addition we utilise routine data available about the patients' GP and district nursing team (jointly referred to as the primary health care team - PHCT). These are GP list size (including number of rural patients), number of partners in GP practice, whether the practice is a training or fundholding practice, whether the district nursing team is located in the GP surgery or not, the size of the district nursing team and the number of RGN nurses. There is to our knowledge no previous findings relating to the characteristics of the PHCT and referral to home care or place of death. However, the PHCT is of considerable importance in the organisation of home care, and routine data about the team may provide valuable insights in the current study. Most people who die and who therefore may require palliative care, are over 65 (Higginson, 1997, 1999). GP list size of patients over age 65 may therefore indicate the extent to which the GP is likely to have been exposed to palliative care in his/her practice. The proportion of rural patients on the GP list is an indicator of rural versus urban location, which may have an impact on use of centralised inpatient care versus outreach home care services. The number of partners at the surgery, district nursing team size and the number of qualified nurses on the team reflect the resources that the PHCT itself can draw on in provision of care at home. GP fundholding, which still was in effect at the time of the study, may have had an impact on purchase of community nursing from the Lifespan NHS Trust, while training practice status reflects the surgery's likelihood of keeping abreast of new developments and embracing innovation.

The study will furthermore utilise electronic record data on NHS service input other than HAH. These data have been linked to provide information on each patient's inpatient care in the last year of life, in the form of acute hospital care, cardio-thoracic specialist input, continuing care beds and hospice care, and primary

care input, in the form of district nursing, night nursing, Macmillan nursing, Marie Curie nursing, Flexible Care and other NHS community care. Variables considered for each service are whether the patient received the service or not, and, when received, the total amount of input provided and the start date of care relative to date of death.

In terms of case mix we hypothesise that patients who access HAH, are also likely to gain access to other home care services, and to do so earlier than other patients, given a similar level of need. Thus the analysis will consider whether HAH patients differ from other patients in terms of the non-HAH service resources (particularly community) on which they can draw, and in terms of how early they were able to access such services.

Furthermore, when considering variables associated with home death, monitoring of service input other than HAH is also important. As noted, district nursing care has been associated with death at home in the past, while inpatient care has been related to inpatient death, although the direction of cause and effect is difficult to establish. The underlying hypothesis of the thesis is that the more professional resources available to the patient in the home, the better. Furthermore, it has been hypothesised that early rather than later contact with community services, particularly district nursing, is beneficial for the management of terminal care at home (Cartwright, 1991, Grande et al, 1997). Both the level of NHS input and when it began are likely to be important in relation to place of death.

2.2.3 Data collection

- Demographic and clinical data

EACR data were provided by the Cambridge Cancer Intelligence Unit. This yielded data on the diagnostic ICD9 or ICD10 code, date of diagnosis, cause of death, age and sex, and whether the patient had been in contact with a hospital, and if so, with an oncology specialist. The Cancer Intelligence Unit also provided

the Jarman Underprivileged area score (UPA) and Townsend Index score for the patient's ward of residence (Jarman, 1983, 1984, Townsend et al, 1988).

Data on place of death and occupation were obtained from the Office of National Statistics (ONS) and the Cambridge and Huntingdon Health Authority (CHHA). Data on the patient's GP was obtained from the CHHA, including GP list size and whether the surgery was a fundholding or training practice. Data on the district nursing team were obtained from the Lifespan Healthcare NHS Trust.

It was not possible to obtain complete and reliable information on marital status from the information available. The EACR could provide information on marital status for only 61% of patients. Further information could be obtained from the ONS death certificates for women but not for men. In the end marital status could be obtained for 58% of men and 83% of women. An analysis of marital status will be presented, but its value is limited given the large proportion of missing data.

- Service utilisation data

Electronic record data on NHS input in the last year of life were extracted and linked from different sources. An experienced computer assistant was employed to carry out this task in accord with the specifications of the researcher. In larger scale data linkage projects individual health event records have been matched with probability scores against known patient attributes (Gill et al, 1993). For this small scale project it was considered that the appropriate method would be to determine the internal patient identifier or reference number used within each database system and to use this as a key to extraction of the relevant events.

Most of the NHS systems used had sophisticated routines to support 'fuzzy' matching of patient details. A standard matching algorithm was devised by the computer assistant and followed within these systems. This included Soundex code name search (i.e. reducing names to phonetic codes which are less vulnerable to variations in spelling, Gill et al, 1993) and date of birth searches with controlled variations to year,

month and day. A variety of corroborating patient attributes were then used to validate the patient identifiers. For a small number of patients multiple identifiers were found, but in most cases old identifiers had been marked as obsolete. For these obsolete identifiers checks were made to ensure that relevant health events had been transferred to the new identifier. In only one case was it necessary to extract events using two identifiers.

The patient identifiers were used as a key to the extraction of health care events recorded within the source NHS IT systems. The routine uses of the data within these systems are for support of ongoing care of patients and provision of management information (in aggregated form), and do not typically include the extraction of detailed electronic histories for individual patients. Expert local knowledge and assistance were provided by the relevant NHS IT departments in identifying the available data and assembling it in a suitable form.

Addenbrooke's Hospital inpatient and outpatient data were collected from the Addenbrooke's HISS database. Papworth hospital inpatient data were collected from the Papworth PAS system. However, Papworth outpatient data were not available. Arthur Rank Hospice inpatient data and other Lifespan inpatient input were obtained from the Lifespan Healthcare NHS Community Trust PAS database. District nursing, Macmillan nursing and other Lifespan community input (e.g. physiotherapy) was obtained from the Lifespan Comwise database. Flexible Care nursing data were obtained from the Flexible Care database at the Princess of Wales Hospital.

No electronic system existed within the Lifespan NHS Community Trust to record care delivered to patients at home by the Marie Curie and HAH nursing teams. A computer system to collect these data as an integral part of the normal administration of Palliative Care Services was therefore designed by the computer assistant for routine use within the Trust. Paper records of previous Marie Curie events were identified and added to this system for patients referred to HAH and for patients in the CR group.

Data from each source were collected for the patient's last year of life, with the exception of Addenbrooke's outpatient data, for which information was only available for the last three months of life. The possibility of including Social Service data was investigated through discussions with Social Service representatives. However, this information was not recorded in such a format that the hours of input and type of care could be extracted for individual patients. Collection of data on private hospital care was not possible within the scope of the study (For the present sample our data show that two of 200 inpatient deaths occurred in private hospitals. Thus the private hospital input was probably quite limited).

Whilst every effort was made to ensure that the data set was complete, some patient data may have been missed due to failure to find a database match e.g. through misspelled surnames or incorrect date of birth. However, the adoption of several identification procedures in identifying patients should keep this to a minimum. The quality of the data extracted furthermore depends on the quality of the data entry for individual databases. However, there is no *a priori* reason to believe that the degree of data recording error should be different for our two patient groups. Provided the recording errors are randomly distributed, they should not introduce bias into our analysis of differences between the HAH and CR sample.

2.2.4 Data preparation

Record formats of the extracted NHS input data varied among systems and in some instances between types of care within a system. The computer assistant transformed the data into a common format with a program that also removed potential errors from the electronic information obtained, including home visits recorded during the middle of an inpatient stay and recorded input to patients after their date of death. These records may have been correct as community nurses may visit the patient's home either mistakenly or for assessment of the home during an inpatient stay. Similarly district nurses may pay bereavement visits to the patient's family. However, as such recorded visits were not directly associated with the patient's care or potential errors, they were excluded.

Dates for care input were translated into days before death for each patient. Thus for each service a start date for onset of care could be calculated, expressed as number of days before death. Number of inpatient days were available for secondary care and number of appointments for acute hospital outpatient appointments and day cases. Hours of care were available for community nursing.

Cancer diagnosis was obtained from the East Anglian Cancer Registry (EACR). If a patient had more than one registry entry, i.e. had more than one cancer diagnosed, the last entry was chosen for the patient's diagnosis and diagnosis date (unless this was a benign tumour or a non-melanoma skin cancer). The last entry was assumed to be most closely linked to cause of death, while a first entry may represent a cancer which was cured. When using the last entry, there was close correspondence between the EACR diagnosis and recorded cause of death in 303 (93%) of 327 cases. For 13 (54%) of the remaining 24 cases a specific cancer was recorded in the EACR diagnosis while a "malignant neoplasm of ill-defined, secondary and unspecified site" (ICD10 definition) was recorded as a cause of death. The ICD codes were grouped to correspond to the cancer categories found to be of importance in past research, notably breast, gastrointestinal, genitourinary, respiratory, haematological, CNS and head/neck cancers. The remainder were grouped into "other" cancers.

Data on patient occupation or occupation of husband were allocated to SOC Occupational Unit Groups, and the patient's Social Class subsequently derived from these codes (OPCS, 1990, 1991). If the information was sufficiently vague to fit more than one social class grouping, the lowest was coded, in accord with discussions with ONS staff. The rationale is that there are likely to be fewer people in the highest than the lowest status occupations. For instance, an accountant can be social class I, II or IIIN depending on type, but he or she has greatest likelihood of being in IIIN. This may lead to a bias towards coding lower classes, but this bias will be of similar magnitude for both HAH and CR patients.

2.2.5 Analysis and statistical tests

- Treatment of service variables

Initial consideration of the service data showed that for each service the majority, or a considerable proportion, of patients had received no input. Consequently, a first analysis of service input only compared the proportion of patients who had received care from each service. To gain further insight into service delivery when care was provided, a second analysis compared the actual amount of care and the onset of care for those patients who received input from a service. This was preferred to comparing averages of amount and onset of care for the total patient samples, as the resulting means or medians would largely have been determined by the number of zero values in each comparison group. Any real differences in patterns of service delivery could therefore easily be masked. Likewise, if differences were observed, it would be difficult to establish whether such differences were simply due to the difference in number of patients who accessed the service, or to actual differences in the amount and onset of care provided.

In order to understand patterns of care better, both amount and onset of care were considered in the univariate analysis. However, as these dimensions are likely to be positively correlated, they were not entered together in the same logistic regression analysis, as they may mask each other's association with the dependent variable (Norusis, 1994). Amount and onset were therefore investigated separately in the logistic regression analysis.

- Statistical tests

Cohen's Kappa (Cohen, 1960) was used to check for correspondence between HAH referral record and electronic record accounts of which patients had received HAH care.

For comparison of proportions X^2 tests with Yates's continuity correction was used for 2x2 tables, as this test is recommended for n>40 (Siegel and Castellan, 1991). Fisher exact test was used for 2x2 tables if any of the cells had expected frequency of less than five. For tables with more than four cells the Pearson's X^2

test was used if fewer than 20% of the cells had an expected frequency of less than five and none had an expected frequency of less than one (Siegel and Castellan, 1991). If the table violated this assumption, cells with low frequencies were collapsed to meet the requirements of the test.

Mann-Whitney U tests were used for comparing UPA and Townsend scores of deprivation. As values on these variables relate to wards in a relatively small geographical area, variables were clustered rather than continuous, and a non-parametric test was considered more appropriate. The Student t-test was used for age, GP list sizes and number of GP partners. The Log Rank statistic was used to test for equality of survival distributions for the two samples.

Mann-Whitney U tests were used to compare amount and onset of care for patients who received service input. A non-parametric test was chosen because it was clear that the service data were far from normally distributed, even when zero values were removed from analysis. The distribution of amount and onset of care clustered around the lower values with few patients achieving high amounts or early onset of care (calculated as days from death). While all patients who received care will have had at least one day or one half hour of input, the patient attrition typical for palliative care means that only a small proportion of patients are able to accumulate a large total amount of care. Likewise the need for care will predominantly occur close to death, so values for onset of care will cluster around a few days before death. For the same reasons a non-parametric test, the Spearman rank-order correlation coefficient, corrected for ties, was used to assess relationships between amount and onset of care for each NHS service.

Forward stepwise logistic regression was used. Hosmer and Lemeshow (1989) note that this method is particularly useful when there are a large number of variables to be entered into the regression. Altman (1991) questions the value of using univariate analysis to decide which variables to explore in the multivariate analysis, when employing forward stepwise regression. As this regression procedure enters variables on the basis of their level of significance, beginning with the most significant variable, the process itself removes variables of no relevance. However, in the present study the univariate analysis was

in itself important to aid our understanding of case mix and the characteristics of the variables under study, particularly of service variables and their appropriate treatment.

The percentage of cases classified correctly and the goodness of fit were used to assess the resulting logistic regression models. The goodness of fit statistic is the sum of the squared standardised residuals, where the residual is the difference between the observed probability of home death and the predicted probability based on the model (Norusis, 1994). As the number of patients entering analysis is always the same, it should be possible to compare goodness of fit between different models. The model chi square values are also reported. However, as these are dependent on the number of variables in the model, and the reported models contain different numbers of variables, the model chi square was not used for comparison (Hosmer and Lemeshow, 1989).

The statistical software used was SPSS for Windows 6.0 and 6.1. All tests were two-tailed.

- Logistic regression entry criteria

Variables which showed a difference between samples in the univariate analysis at $p<0.2$ were considered for entry into multiple logistic regression analysis. A lax criterion for entry of $p<0.2$ is recommended by Altman (1990) and Hosmer and Lemeshow (1989), as variables may contribute to the model in unforeseen ways due to complex interrelationships between the variables. Within the SPSS forward stepwise logistic regression procedure, the probability level for entry into the model was set to $p<0.05$ (Norusis, 1994). This is a measure of the relative importance of a variable compared to other variables entered into the regression analysis, and is different from significance levels obtained from univariate analysis (Hosmer and Lemeshow, 1989).

- Outline of logistic regression analyses

To establish to what extent identified case mix variables on their own appear to predict place of death, multiple logistic regression was initially performed with only these variables; first with demographic and clinical variables for which we currently have the best understanding; second with service variables added to the clinical and demographic variables. Similarly to access to HAH, other service input may be associated with demographic and clinical variables. This may to some extent be assessed by observing any changes in the coefficients for the demographic and clinical variables when service variables are entered into the analysis. A considerable change would suggest interdependence between demographic, clinical and service variables (Hosmer and Lemeshow, 1989).

In a final logistic regression analysis HAH input was entered alongside all the other variables to allow assessment of association between HAH and home death when case mix variables were controlled for. Any interdependence between HAH and other variables could be assessed by considering changes in coefficients between the models with and without HAH.

2.3 OBSERVATIONAL STUDY RESULTS

Section 2.3.1 reports the size of the study samples. Section 2.3.2 compares electronic record data on HAH input with HAH records of admissions. Section 2.3.3 investigates the relationship between HAH and place of death. Both referral to HAH and actual admission to the service were considered.

In section 2.3.4 the HAH and CR group are compared on demographic, clinical and service variables using univariate analysis. Section 2.3.5 reports the differences between patients who were admitted to HAH and those only referred but not admitted. The results of the univariate analyses are briefly summarised in section 2.3.6.

Section 2.3.7 explains the selection and preparation of variables for logistic regression analysis. Section 2.3.8 reports a logistic regression analysis of the association between demographic and clinical variables and place of death. Section 2.3.9 presents an analysis in which service variables are entered alongside the demographic and clinical variables. Finally, in section 2.3.10 the association between HAH and home death is investigated alongside service, demographic and clinical variables. This final analysis should allow assessment of the relative contribution of HAH input to home death alongside case mix variables.

2.3.1 Size of recruited patient samples

- Patients referred to HAH

Between 16th June 1994 and 19th June 1995 158 patients were referred to HAH. Twenty six patients who had not died by the end of October 1995 and/or were recorded with a non-cancer diagnosis were excluded from analysis. A further eleven patients were also excluded: three were not found on the local cancer registry nor neighbouring registries, thus their diagnosis of cancer is uncertain; three had no record of cancer as a cause of death and may not have died from their cancer; five patients were registered outside the region. In total 121 HAH patients entered the analysis.

- Patients identified through the East Anglian Cancer Registry (EACR)

299 records were randomly selected from the total set of EACR entries of patients resident within the former Cambridge Health District, who died within the same period as the HAH cancer patients and were not referred to HAH between June 1994 - June 1995. The aim was to obtain a 1:2 sample of HAH patients versus controls. However, slightly more entries had to be excluded than had been expected. In twelve cases a patient had more than one entry (i.e. a second diagnosis had been made). In these cases the first entry was omitted from analysis and the last entry retained (unless benign tumour or non-melanoma skin cancer). Twelve patients were found to have been referred to HAH after 19th June 1995 and excluded. Fourteen patients were excluded because more recent NHS and Death Certificate records suggested they were not

resident in the former Cambridge Health District towards the end of life, and one patient due to death at the age of twelve. The remaining 260 patients represented 27% of the patients on the EACR who died within the same period as the HAH patients, were resident in the former Cambridge Health District and who were not referred to HAH.

Of the remaining 260 CR patients, 54 (21%) did not have cancer recorded as a cause of death and may therefore not have died from their cancer. Thus 206 patients from the EACR entered analysis.

2.3.2 Verification of HAH record data

According to HAH records, 62 (51%) of the 121 patients referred to HAH were admitted to the service and 59 (49%) not admitted.

Table 2.1 shows the correspondence between HAH records of patients admitted to HAH, and patients admitted to HAH according to electronic record data of HAH care. This yields a Kappa value of 0.884, indicative of almost perfect agreement between HAH records and record linkage data (Landis and Koch, 1977).

Table 2.1: Correspondence between HAH records and record linkage data regarding HAH input.

	HAH records	
Record linkage	No HAH	HAH
No HAH	56 (94.9%)	4 (6.5)
HAH	3 (5.1%)	58 (93.5%)

Where discrepancies exist, these are very small. In four cases electronic data showed no HAH input when the HAH records recorded a HAH admission. These represented short HAH care episodes, in which care ended within two days of admission. In three cases electronic data showed HAH input when HAH records showed none. These cases at most had only two visits recorded electronically, none exceeding a total of 15.5 hours of care. When comparing patients admitted to HAH with patients referred but not admitted

(Section 2.3.5), the HAH records were used to decide which of the HAH referrals were admitted to the service.

2.3.3 Univariate analysis of the relationship between HAH and place of death

In total 127 (39%) of 327 patients died at home. The remaining patients died in hospital (n=115, 35%), hospice (n=76, 23%), residential or nursing homes (n=8, 2%) or on the way to hospital (n=1, 0.3%). These deaths will collectively be referred to as inpatient deaths.

Table 2.2: Place of death by patient group. n (%)

Place of death	CR Group	HAH group		Significance level
	n (%)	Referred, not admitted HAH n (%)	Admitted HAH n (%)	
At home	48 (23.3)	26 (44.1)	53 (85.5)	X^2=78.405, d.f.=2, p<0.0001
In inpatient care	158 (76.7)	33 (55.9)	9 (14.5)	

Table 2.2 shows that 86% of patients who were admitted to HAH died at home, compared to only 23% of the CR group. There is therefore an association between HAH care and death at home. Merely being referred to HAH is also associated with greater likelihood of dying at home. Nearly twice as many of patients referred to HAH but not admitted (44%) died at home compared to the CR group.

To further explore the association between HAH care and place of death, amount and onset of HAH care was compared between those who died at home and in inpatient care.

Table 2.3: Amount and onset of HAH input by place of death, patients admitted to HAH only

	Amount of HAH care (hours) Median (i.q.r.)	Onset of HAH care (days before death) Median (i.q.r.)
Home death (n=53)	34.5 (63.3)	5 (8.0)
Inpatient death (n=9)	18.5 (49.0)	24 (83.0)
Significance level	Z=0.740, p=0.460	Z=3.448, p=0.001

Among patient who received HAH care, patients who died at home did not have significantly more hours of HAH care than those who died as inpatients. However, those who died at home began their HAH care significantly closer to death (5 versus 24 days). Thus HAH care was associated with home death, but so was referral to the service *per se*. This may already indicate there is an effect of case mix. When HAH care was received, the timing of HAH input may be important in relation to place of death.

2.3.4 Comparing patients referred to HAH with patients not referred

This section compares the characteristics of patients referred to HAH with a similar sample of patients not referred. In the next section we consider the patients referred to HAH in more detail, by comparing the patients admitted to HAH with those referred but not admitted. When describing group differences, the emphasis will be on variables which differ at $p<0.05$. However, as variables which differ at $p<0.2$ will be entered into the logistic regression analysis, brief mention will also be made of these.

- Demographic and clinical variables

Table 2.4 compares the CR and HAH groups on demographic and clinical variables. Table 2.5 compares the two patient groups on characteristics of their GP surgery and district nursing team.

At $p<0.05$ the HAH group were significantly more likely to have only cancer recorded as cause of death compared to the CR group. The CR group was more likely to have been diagnosed within a month of diagnosis. The HAH group was younger and lived in areas with a lower median Jarman and Townsend deprivation scores than the CR group, but no difference was found in terms of social class as defined by occupation. Variables differing at $p<0.2$ which were also included into the logistic regression were diagnosis, number of partners in patient's GP practice, and practice fundholding status.

Table 2.4: Demographic and clinical characteristics; n=121 for HAH group and n=206 for CR group unless otherwise specified

	CR group	HAH group	Significance levels
CAUSE OF DEATH:	**n (%)**	**n (%)**	
Cancer only cause	110 (53.4)	99 (81.8)	
One other cause recorded alongside cancer	62 (30.1)	18 (14.9)	
Two other causes recorded alongside cancer	34 (16.5)	4 (3.3)	X^2= 28.28, d.f.=2, p<0.0001
SURVIVAL:	**Median (i.q.r.)**	**Median (i.q.r.)**	
Days between diagnosis and death.	363 (1053)	257 (799)	Log Rank statistic=1.04, d.f.=1, p=0.3079
Patients diagnosed within a month of death.	**n (%)** 38 (18.4)	**n (%)** 7 (5.8)	X^2 = 9.258, d.f.=1, p=0.002
DIAGNOSIS:	**n (%)**	**n (%)**	
Breast	28 (13.6)	13 (10.7)	
Central nervous system	4 (1.9)	6 (5.0)	
Gastro-intestinal	52 (25.2)	40 (33.1)	
Genito-urinary	45 (21.8)	16 (13.2)	
Haemotologial cancers	20 (9.7)	7 (5.8)	
Respiratory	34 (16.5)	19 (15.7)	
Head and neck	5 (2.4)	2 (1.7)	
Other[1]	28 (13.6)	28 (23.1)	X^2=12.194, d.f.=7, p=0.094
AGE:	**Mean (s.d.)**	**Mean (s.d.)**	
	74.7 (12.0)	70.5 (13.8)	t=2.77, d.f.=224.23, p=0.006
SEX:	**n (%)**	**n (%)**	
Females	105 (51.0)	68 (56.2)	
Males	101 (49.0)	53 (43.8)	X^2=0.836, d.f.=1, p=0.361
MARRIED:	**n (%)**	**n (%)**	
Females – Yes	45 (51.1)	30 (53.6)	
- No	43 (48.9)	26 (46.4)	X^2=0.01, d.f.=1, p=0.909
Males - Yes	37 (67.3)	27 (77.1)	
- No	18 (32.7)	8 (22.9)	X^2=0.591, d.f.=1, p=0.442
SOCIOECONOMIC AREA:	**Median (i.q.r.)**	**Median (i.q.r.)**	
Jarman UPA score.	-0.72 (20.01)	-3.03 (18.95)	Z=2.3340, p=0.0196
Townsend index.	-0.38 (3.42)	-1.08 (3.99)	Z=2.3667, p=0.0179
SOCIAL CLASS:	**n (%)**	**n (%)**	
I	12 (5.9)	13 (11.2)	
II	57 (28.2)	36 (31.0)	
IIIN	17 (8.4)	12 (10.3)	
IIIM	59 (29.2)	30 (25.9)	
IV	52 (25.7)	22 (19.0)	(HAH n=116, CR n=202)
V	5 (2.5)	3 (2.6)	X^2=4.85, d.f.=5, p=0.43413

[1] Cancers of ill-defined, secondary and unspecified sites, intrathoracic organs and thyroid, melanomas, mesotheliomas, and cancers of other digestive organs than GI tract.

Table 2.5: GP and district nurse characteristics

	CR group	HAH group	Significance levels
GP LIST SIZES	**Mean (s.d.)** (n=161)	**Mean (s.d.)** (n=108)	
GP total list size	1856 (457)	1801 (500)	t=0.922, d.f.=267, p=0.357
List size aged 65-74	166 (79)	162 (82)	t=0.354, d.f.=267, p=0.724
List size aged > 75	152 (66)	149 (73)	t=0.366, d.f.=267, p=0.715
Proportion of rural patients	0.29 (0.51)	0.34 (0.60)	t=0.720, d.f.=267, p=0.472
GP PRACTICE CHARACTERISTICS	**Median (i.q.r.)** (n=191)	**Median (i.q.r.)** (n=121)	
Number of partners	5 (2)	5 (2)	Z=1.327, p=0.185
Training practice:	**n (%)**	**n (%)**	X^2=0.864, d.f.=1, p=0.353
Yes	119 (62.3)	67 (56.3)	
No	72 (37.7)	52 (43.7)	
Fundholding practice:	**n (%)**	**n (%)**	X^2=2.825, d.f.=1, p=0.093
Yes	49 (25.7)	20 (16.8)	
No	142 (74.3)	99 (83.2)	
DISTRICT NURSE TEAM			
Team based at surgery:	**n (%)**	**n (%)**	
Yes	122 (65.2)	78 (66.7)	
No	65 (34.8)	39 (33.3)	X^2=0.017, d.f.=1, p=0.896
Team size:	**Median (i.q.r.)** (n=183)	**Median (i.q.r.)** (n=113)	
	4 (2)	4 (2)	Z=0.7511, p=0.4526
DN sisters and RGNs in team:	**Median (i.q.r.)** (n=185)	**Median (i.q.r.)** (n=115)	
	2 (2)	2 (2)	Z=0.3614, p=0.7178

- NHS service input

East Anglian Cancer Registry (EACR) records of hospital input are briefly considered before reporting electronic record linkage data on NHS service input. The EACR data only records whether a patient has been in contact with a hospital in general or an oncology department during their illness history. The record linkage data give more detailed description of NHS input in the last year of life.

Table 2.6 shows the EARC data. While HAH and CR group patients were equally likely to have been in contact with a hospital, HAH group patients were significantly more likely to have been in contact with an oncology department.

Table 2.6: Percentage of patients recorded on the Cancer Registry to have been in contact with a hospital or with a hospital oncology department

	CR group	HAH group	Significance level
In contact with hospital:			
Yes	189 (92)	115 (95)	
No	17 (8.3)	6 (5.0)	X^2=0.811, d.f.=1., p=0.368
In contact with an oncology department:			
Yes	83 (40.0)	69 (57.0)	
No	123 (59.7)	52 (43.0)	X^2=7.921, d.f.=1, p=0.005

Table 2.7 shows the proportion of patients who received care from an NHS service according to the electronic record linkage data.

Table 2.7: Number (percentage) of patients who received a service in their last year of life

	CR group n=206	HAH group N=121	Significance level
Acute hospital inpatient	145 (70.4)	93 (76.9)	X^2=1.301, d.f.=1, p=0.254
Acute hospital daycase	37 (18.0)	26 (21.5)	X^2=0.404, d.f.=1, p=0.525
Acute hospital outpatient[1]	110 (53.4)	73 (60.3)	X^2=1.219, d.f.=1, p=0.270
Hospice inpatient	44 (21.4)	46 (38.0)	X^2=10.390, d.f.=1, p=0.001
Continuing care beds	10 (4.9)	4 (3.3)	X^2=0.148, d.f.=1, p=0.700
Cardio-thoracic specialist inpatient	22 (10.7)	10 (8.3)	X^2=0.267, d.f.=1, p=0.605
District nursing	125 (60.7)	111 (91.7)	X^2= 35.075, d.f.=1, p<0.0001
Night nursing	18 (8.7)	31 (25.6)	X^2= 15.754, d.f.=1, p<0.0001
Macmillan nursing	27 (13.1)	45 (37.2)	X^2= 24.365, d.f.=1, p<0.0001
Marie Curie	17 (8.3)	76 (62.8)	X^2=108.819, d.f.=1, p<0.0001
Other community trust care	17 (8.3)	20 (16.5)	X^2=4.411, d.f.=1, p=0.036
Flexible care	7 (3.4)	23 (19.0)	X^2=20.548, d.f.=1, p<0.0001

The HAH group was more likely than the CR group to have received hospice care, district nursing, night nursing, Macmillan nursing, Marie Curie nursing, other community trust primary care, such as occupational therapy or physiotherapy, and Flexible care, all at $p<0.05$. Thus patients referred to HAH were overall more likely to receive palliative care and community services than the CR group.

The subsequent analysis considers whether the pattern of service delivery differs between the two groups in terms of amount and onset of care for those patients who received a service. Table 2.8 shows that when

patients received input from a service, the HAH group received a greater amount of district nursing input than the CR group, while the CR group received a greater amount of Flexible care nursing, both at $p<0.05$.

Table 2.8: Amount of input per patient in the last year of life for those patients who had a service. Median (interquartile range). Mann-Whitney U-tests used for comparison.

	CR group	n	HAH group	n	Significance level
Acute hospital inpatient days	17 (28.5)	145	20 (21)	93	Z=0.405, p=0.685
Acute hospital daycase appointment	2 (5.5)	37	1.5 (3.3)	26	Z=0.762, p=0.446
Acute hospital outpatient appointment[1]	2 (2)	110	2 (2)	73	Z=0.225, p=0.822
Hospice inpatient days	12 (16.5)	44	13.5 (14)	46	Z=0.299, p=0.765
Continuing care bed days	18.5 (52.3)	10	16.5 (64.3)	4	Z=0.071, p=0.944
Cardio-thoracic specialist inpatient care days	12.5 (17.5)	22	16 (25)	10	Z=0.448, p=0.654
District nursing hours	6.8 (16.8)	125	19.1 (23.8)	111	Z=5.814, p<0.0001
Night nursing hours	2.4 (5.4)	18	3 (4.4)	31	
Macmillan nursing hours	2.3 (3.2)	27	2.2 (4.3)	45	Z=0.169, p=0.866
Marie Curie nursing hours	18 (97)	17	27.5 (51)	76	Z=0.005, p=0.996
Other community trust hours	1.1 (1.2)	17	1.8 (1.8)	20	Z=0.794, p=0.427
Flexible care hours	23.5 (60.8)	7	6 (14)	23	Z=2.112, p=0.035

Table 2.9 shows that when patients received care from a service, the HAH group began their district nursing and other community trust primary care closer to death than the CR group. Conversely, the HAH group began their cardio-thoracic specialist input earlier than the CR group (all $p<0.05$).

Table 2.9: Onset of care for those patients who received a service. Days before death. Median (interquartile range).

	CR group	n	HAH group	n	Significance level
Acute hospital inpatient	132 (219.5)	145	136 (161)	93	Z=0.653, p=0.514
Acute hospital daycase	191 (226)	37	190 (117)	26	Z=0.202, p=0.840
Hospice inpatient	12.5 (41)	44	19 (34.8)	46	Z=0.885, p=0.376
Continuing care beds	45 (152)	10	37.5 (67.3)	4	Z=0.283, p=0.777
Cardio-thoracic specialist inpatient care	117 (104.5)	22	234 (210.5)	10	Z=2.074, p=0.038
District nursing	109 (236.5)	125	85 (145)	111	Z=2.200, p=0.028
Night nursing	13 (57)	18	9 (18)	31	Z=0.312, p=0.755
Macmillan nursing	86 (115)	27	86 (129)	45	Z=0.227, p=0.821
Marie Curie nursing	21 (91)	17	19.5 (37.8)	76	Z=0.577, p=0.564
Other community trust care	74 (126)	17	32.5 (70.8)	20	Z=2.073, p=0.038
Flexible care	55 (56)	7	18 (43)	23	Z=1.569, p=0.117

2.3.5 Comparing patients admitted to HAH with patients referred but not admitted

This section considers patients referred to HAH in more detail. Patients who were referred to HAH but not admitted to the service were compared with patients admitted to HAH. The former is referred to as non-admitted HAH patients and the latter as admitted HAH patients. Appendix 2, Tables 2.1-2.6 show the full results, and only a summary is provided here.

There were no significant demographic or clinical differences between the two groups. Non-admitted HAH patients were significantly more likely to have had hospice input and less likely to have had Marie Curie care than admitted HAH patients. When care was received, admitted HAH patients received significantly more hours of district nursing care than non-admitted HAH patients (all $p<0.05$).

In terms of variables which differed at $p<0.2$ and therefore would enter the logistic regression analysis, most had already been identified in the previous section. The only new variables at $p<0.2$ identified in the present analysis was marital status for women but not men, GP total list size and number of continuing care bed days.

2.3.6 Summary of variables for entry into multivariate logistic regression

Tables 2.10a, b and c below summarise the variables which differed between comparison groups at $p<0.2$ or less and which therefore will be considered for entry into the logistic regression alongside HAH input.

Table 2.10a: Demographic and clinical variables differing between patient groups at p<0.2.

	CR group versus HAH group	Admitted versus Non-admitted HAH patients
Number of non-cancer causes of death	p<0.05	
Death within a month of diagnosis	p<0.05	
Diagnosis	p<0.1	
Age	p<0.05	
Townsend index	p<0.05	
Jarman index	p<0.05	p<0.2
Marital status (females)		p<0.2
Total GP list size		p<0.2
No of GP partners	p<0.2	
Fundholding practice	p<0.1	

Table 2.10b: Service input variables differing between the CR and HAH group at p<0.2.

	Input/ no input	Amount of input	Onset of care	n receiving care
Hospice inpatient	p<0.05			90
Cardio-thoracic specialist inpatient care			p<0.05	32
Continuing care beds				14
District nursing	p<0.05	p<0.05	p<0.05	236
Night nursing	p<0.05			49
Macmillan nursing	p<0.05			72
Marie Curie nursing	p<0.05			93
Other community trust care	p<0.05		p<0.05	37
Flexible Care	p<0.05	p<0.05	p<0.2	30
Oncology specialist care	p<0.05	N/A	N/A	152

Table 2.10c: Service input variables differing between admitted versus non-admitted HAH patients at p<0.2.

	Input/ no input	Amount of input	Onset of care	n receiving care
Hospice inpatient	p<0.05		p<0.2	46
Cardio-thoracic specialist inpatient care				10
Continuing care beds		p<0.2 *	p<0.2*	4
District nursing		p<0.05		111
Night nursing				31
Macmillan nursing				45
Marie Curie nursing	p<0.05	p<0.1		76
Other community trust care				20
Flexible Care	p<0.1			23
Oncology specialist care		N/A	N/A	

* low numbers in one category

2.3.7 Treatment of variables for entry into logistic regression analysis

The Townsend and Jarman indices are closely related, thus only one should be selected for analysis (Norusis, 1994). The Jarman UPA score was chosen because it differed both between the CR and the HAH group, and between admitted and non-admitted HAH patients (the latter only at $p<0.2$). However, one should note that the Jarman index to a large extent is an indicator of GP workload (Jarman, 1983, 1984) while the Townsend probably gives a better indication of material wealth (Townsend et al, 1988).

Marital status differed between admitted and non-admitted HAH patients for women only (at $p<0.2$, Appendix 2, Table 2.1). As the behaviour of this variable depended on sex, it was entered as part of an interaction variable between marital status and sex.

The continuous variables age, Jarman UPA score, GP list size and number of GP partners were categorised on the basis of their quartile values as recommended by Hosmer and Lemeshow (1989). The quartile values and resulting patient category numbers are shown in Appendix 2, Table 2.7. Number of non-cancer causes of death was entered as a continuous variable.

Table 2.10b and c suggest that patient groups may differ both in terms of onset and amount of service input. However, onset and amount of care are positively correlated, which makes it difficult to separate out their individual contributions to the model if they are entered together (Norusis, 1994). This positive correlation stems not only from sharing the same zero values. An early onset of care is also likely to be associated with a higher total amount of input, because the time in which input can be provided is longer. Conversely, a late onset leaves little time for input and is likely to be associated with low total care input. Both late onset and high amount of input were associated with home death for district nursing. However, the correlation between onset and amount of input is overall a positive one. Table 2.11 shows their correlations with zero values excluded. Both dimensions should therefore not be entered as separate variables into the same logistic regression. Either only one dimension should be entered for each service (i.e. amount and onset

analysed separately), or a combined amount/onset variable be constructed where patient numbers are large enough to sustain a high number of subdivisions.

Table 2.11: Correlation between amount and onset of care. Patients receiving input only.

	Spearman rank order correlation coefficient	Significance level
Hospice inpatient (n=90)	0.8653	p=0.000
Cardio-thoracic specialist inpatient (n=32)	0.0597	p=0.746
Continuing care beds (n=14)	0.7745	p=0.001
District nursing (n=236)	0.3096	p=0.000
Night nursing (n=49)	0.4059	p=0.004
Macmillan (n=72)	0.4372	p=0.000
Marie Curie (n=93)	0.6852	p=0.000
Other community trust care (n=37)	0.0658	p=0.699
Flexible care (n=30)	0.5528	p=0.002

In the subsequent analysis onset and amount of care were analysed separately. Most service variables were categorised into "no input", "early onset" and "late onset", or "no input", "low amount" and "high amount". District nursing was, however, categorised on the basis of both amount and input, as the number of patients receiving district nursing was sufficiently large to sustain such a division. The resulting categories were "no input", "early onset/high input", "early onset/low amount", "late onset/high amount" and "late onset/low amount". The medians of amount and onset of input for patients receiving care were used for the subdivisions. Appendix 2, Tables 2.8-2.10 show the medians and resulting patient numbers in each category. Contact with oncology specialist services could only be entered as "input" versus "no input".

Repeated contrasts were used to assess whether regression coefficients of the designed subcategories are significantly different and therefore informative to the present study. Repeated contrasts in logistic regression is a procedure which compares each category of a predictor variable with the category that precedes it (Norusis, 1994).

If timing of onset of care proves to have predictive value for place of death in the logistic regression, we need to be aware that part of the relationship could be due to differences in amount, in light of the positive relation between onset and amount, and vice versa .

2.3.8 Logistic regression: demographic and clinical variables

On the basis of Table 2.10a the demographic and clinical variables entered into the first logistic regression were number of non-cancer causes, death within a month of diagnosis, diagnosis, age, Jarman index score, marital status, GP list size, number of GP partners and fundholding practice status.

There were missing values for marital status, GP list size, fundholding status and number of GP partners (see Table 2.4 and 2.5). The inclusion of these variables limited the logistic regression sample size to the patients for whom these data were available. As an initial model showed these variables to have no significant association with home death, a second logistic regression analysis was conducted with these variables excluded, so that the total patient sample could be utilised. (Score statistic for these variables in the initial model: marital status/sex 2.559, d.f.=2, p=0.278; GP list size 3.492, d.f.=3, p=0.322; GP partners 2.828, d.f.=3, p=0.419; fundholding status 1.259, d.f.=1, p=0.262)

Table 2.12 shows the resulting model with only non-cancer causes, death within a month of diagnosis, diagnosis, age and Jarman index score entered into the analysis.

Table 2.12: Association between demographic, clinical variables and home death

	Coefficient	SE	P	Odds ratio (95% CI)
Number of non-cancer causes	-0.356	0.181	0.0484	0.700 (0.492, 0.998)
Survival				
Diagnosis within a month of death	-0.907	0.400	0.0233	0.404 (0.184, 0.884)
Diagnosis before last month	*0*			*1*
Constant	-0.642	0.222	0.0038	

n=327, 61.16% of cases correctly classified; Model X^2=12.497, d.f.=2, p=0.0019; number of outliers with SRESID of 2 or more=4; Residual X^2 for variables not in equation=16.704, d.f.=13, p=0.2132; Goodness of fit=328.925.

Only two variables predicted home death at $p<0.05$. Number of non-cancer causes on the death certificate was associated with a decrease in likelihood of death at home. Likewise, diagnosis within a month of death was associated with reduced likelihood of home death compared to earlier diagnosis. None of the variables identified as related to place of death in past research, apart from diagnosis within a month, therefore showed any relation to place of death. Entering age and Jarman UP score as continuous variables yielded an identical model. The model classified only 61% of cases correctly, the same percentage as was obtained with a model based on the constant only. Thus the model based on demographic and clinical variables did not improve our overall ability to predict which patients belonged to the home death group.

2.3.9 Logistic regression: demographic, clinical and service variables

One logistic regression was conducted with all service variables subdivided on the basis of onset of care only, except district nursing, which was categorised both in terms of amount and onset of care. A second logistic regression was conducted with the service variables, except district nursing, subdivided on amount of care. The model based on onset of care appeared more informative for our analysis and is presented below. The model based on amount of care is presented in Appendix 2, Table 2.11, and only a summary is provided in the text.

- Service variables subdivided on the basis of onset

Non-cancer causes, death within a month of diagnosis, diagnosis, age and Jarman index score were entered into the analysis (Table 2.13). Service variables entered were hospice care, cardio-thoracic specialist inpatient care, continuing care bed days, night nursing, Macmillan nursing, Marie Curie nursing, "other" community trust primary care, Flexible care, district nursing and oncology contact. Again initial exploration showed that marital status, GP list size, fundholding status and number of partners did not contribute to the model, and these variables were excluded in subsequent analysis.

The analysis in Table 2.13 uses simple category contrasts to compare each variable category with a reference category (marked by a regression coefficient of zero) (Norusis, 1994). The reference category for service input was always "no input". The same analysis was conducted using repeated contrasts to investigate whether coefficients for variable sub-categories differed significantly and thus had informative value for the study. Those which differed significantly are marked in the table. In the subsequent description of results no assumptions are made about cause and effect between predictor variables and outcome.

Upon entry of service variables into the analysis, any effect of number of non-cancer causes and diagnosis within a month disappeared. This would suggest an interdependence between these variables and service input (Norusis, 1994).

Hospice input was associated with a reduced likelihood of death at home. However, late onset of care was not significantly different from early onset. A late onset of cardio-thoracic specialist care (<123 days from death) was also associated with reduced likelihood of home death, while an early onset was no different from no input.

A high amount of district nursing (>12 hours) was associated with increased likelihood of home death, as was a low amount of district nursing which began close to death. However, a low amount of district nursing which began early (>101 days before death), was no different from no input. A high amount of district nursing which began close to death, thus representing a relatively short period with high input, increased the likelihood of home death more than a high amount with early onset or a low amount with late onset.

A late onset of night nursing (<10 days before death) was associated with increased likelihood of dying at home, while an early onset significantly reduced the likelihood relative to no input. For Marie Curie nursing both a late (<20 days before death) and an early onset of care increased the likelihood of home death compared to no input, and a late onset did so to a significantly greater extent than an early onset.

Table 2.13: Association between demographic, clinical, service input variables and home death. Service variables subdivided on onset of care. Simple contrasts. Variable coefficients which differ significantly at p<0.05 share the same superscript.

	Coefficient	SE	p	Odds Ratio (95% CI)
Hospice inpatient care			<0.0001	
Input, late onset	-2.965	0.622	<0.0001	0.052 (0.015, 0.174)
Input, early onset	-1.905	0.518	0.0002	0.149 (0.054, 0.411)
No input	0			1
Cardio-thoracic specialist inpatient care			0.0328	
Input, late onset	-2.215^{A}	0.956	0.0205	0.109 (0.017, 0.711)
Input, early onset	0.727^{A}	0.640	0.2560	2.069 (0.590, 7.254)
No input	0			1
District nursing care			<0.0001	
Input, amount high, onset late	2.565^{AB}	0.571	<0.0001	13.006 (4.247, 39.830)
Input, amount high, onset early	1.426^{A}	0.483	0.0031	4.163 (1.616, 10.720)
Input, amount low, onset late	0.794^{CB}	0.401	0.0480	2.211 (1.007, 4.855)
Input, amount low, onset early	-0.531^{C}	0.530	0.3163	0.588 (0.208, 1.661)
No input	0			1
Night nursing care			0.0066	
Input, late onset	1.616^{A}	0.752	0.0317	5.032 (1.152, 21.974)
Input, early onset	-1.246^{A}	0.597	0.0369	0.288 (0.089, 0.927)
No input	0			1
Marie Curie care			<0.0001	
Input, late onset	2.481^{A}	0.532	<0.0001	11.953 (4.212, 33.921)
Input, early onset	1.001^{A}	0.491	0.0417	2.720 (1.038, 7.123)
No input	0			1
Constant	-1.120	0.521	0.03217	

n=327, 78.90% cases correctly classified; Model X^2=139.836, d.f.=12, p=0.0000; Number of outliers with SRESID of 2 or more=5; Residual X^2 for variables not in the equation=31.583 with, d.f.=24, p=0.1377; Goodness of Fit=322.136.

The model classified more cases correctly (78.9%) than a model based on demographic and clinical variables only (61.2%), but was better at correctly classifying inpatient deaths (90.0%) than home deaths (61.4%). The goodness of fit was marginally better compared to the previous model (322.1 versus 328.9).

- Service variables subdivided on the basis of amount

The model in which service variables were considered in terms of amount of care (Appendix 2, Table 2.11) proved less informative than one in which onset of care was considered. District nursing care showed the same relationship to place of death as was found in the model based on onset. Compared to no input, hospice care was associated with reduced likelihood of home death and Marie Curie care with increased likelihood, but for neither service was there any significant difference between high and low amount of

input. For these service variables the distinction between high and low input therefore did not prove informative. Neither cardio-thoracic specialist hospital care or night nursing care were included in the final model, suggesting that for these services, neither input or amount per se contributed to the prediction of home death. The model classified somewhat fewer cases correctly (75.8%) than the model based on onset, and this difference mainly lay in the ability to correctly classify home deaths (55.1%) rather than inpatient deaths (89.0%). The goodness of fit (311.0) was, however, better than in the previous model.

2.3.10 Logistic regression: demographic, clinical, service variables and HAH input

- Service variables including HAH subdivided on the basis of onset of care

An analysis in which service variables, including HAH, are subdivided on the basis of onset of care is reported below. A similar analysis in which these variables are subdivided on the basis of amount is reported in Appendix 2, Table 2.12.

The univariate analysis showed that referral to HAH in itself was associated with home death. The HAH variable is therefore categorised into having no input and no referral, referral only, early onset of HAH care and late onset. Onset of HAH care rather than amount showed a difference between those who died at home and those who did not. However, the Spearman rank order correlation coefficient between amount and onset of care for HAH was 0.6387 (patients receiving input only). Therefore, we again need to consider that any differences found in onset of HAH care may partly be a reflection of amount.

Apart from the addition of HAH the variables entered into the present logistic regression are the same as in section 2.3.9. Again initial exploration showed that marital status, GP list size, fundholding status and number of partners did not contribute to the model, leading to their exclusion in the final analysis.

When HAH was entered into the analysis, all the service variables which were present in the previous model remained (section 2.3.9). There were slight changes in their regression coefficients suggesting some

interrelationship with HAH, but the coefficients' magnitude and sign were very similar to those of the model without HAH. This would suggest that these service variables make an independent contribution to place of death which has little impact on the relationship between HAH and place of death and vice versa.

Table 2.14: HAH input, demographic, clinical and service input variables and home death. Service variables subdivided on onset of care. Simple contrasts. Variable coefficients which differ significantly share the same superscript.

	Coefficient	SE	p	Odds Ratio (95% CI)
Hospital at home care			0.0001	
Input, late onset	6.203[A]	1.522	<0.0001	494.205 (25.034, 9756.126)
Input, early onset	1.974[A]	0.767	0.0101	7.198 (1.601, 32.369)
Referral only, no input	1.407	0.455	0.0020	4.083 (1.673, 9.966)
No input and no referral	0			1
Hospice inpatient care			<0.0001	
Input, late onset	-4.084[A]	0.839	<0.0001	0.017 (0.003, 0.087)
Input, early onset	-1.828[A]	0.553	0.0009	0.161 (0.054, 0.475)
No input				1
Cardio-thoracic specialist inpatient care			0.0171	
Input, late onset	-3.157[A]	1.354	0.0197	0.043 (0.003, 0.605)
Input, early onset	1.052[A]	0.653	0.1072	2.862 (0.796, 10.289)
No input	0			1
District nursing care			0.0014	
Input, amount high, onset late	2.076	0.650	0.0014	7.975 (2.229, 28.531)
Input, amount high, onset early	1.440	0.529	0.0065	4.221 (1.497, 11.899)
Input, amount low, onset late	0.617[A]	0.434	0.1550	1.853 (0.792, 4.335)
Input, amount low, onset early	-0.731[A]	0.569	0.1990	0.481 (0.158, 1.469)
No input	0			1
Night nursing care			0.0061	
Input, late onset	2.099[A]	0.897	0.0193	8.157 (1.405, 47.355)
Input, early onset	-1.303[A]	0.647	0.0440	0.272 (0.077, 0.966)
No input	0			1
Marie Curie care			0.0087	
Input, late onset	1.773[A]	0.641	0.0057	5.886 (1.676, 20.672)
Input, early onset	-0.429[A]	0.640	0.5027	0.651 (0.186, 2.282)
No input	0			1
Constant	-0.240	0.643	0.7089	

n=327; 82.57% of cases classified correctly. Model X^2=181.059, d.f.=15, p=0.0000; Number of outliers with SRESID of 2 or more=8; Residual X^2 for variables not in the equation=27.957, d.f.=24, p=0.2618; Goodness of Fit =318.219.

Of all the variables HAH showed the strongest relationship with home death. Both late onset (<=7 days before death) and early onset of HAH care were associated with an increase in likelihood of home death, but late onset significantly more so than early onset. The large coefficient for late onset is associated with a large standard error, and a correspondingly large confidence interval for the odds ratio. This indicates a lack of stability in the model (Hosmer and Lemeshow, 1989). However, it cannot be disputed that HAH shows a considerable, positive association with home death.

However, merely being referred to HAH, without subsequent input, was also associated with a significant increase in the likelihood of dying at home. Furthermore, the regression coefficient for early onset of HAH care is not significantly different from referral only. This indicates an effect of case mix although all known differences between patient groups should have been controlled for.

As in the analysis presented in section 2.3.10, hospice input was associated with a reduced likelihood of home death. In addition late onset of care (<=16 days before death) was significantly more closely associated with home death than early onset. For cardio-thoracic specialist inpatient care late onset again reduced the likelihood of home death while early onset was no different from no input.

For district nursing a high amount of care was associated with increased likelihood of death at home, compared to no input. However, a low amount was not significantly different from no input. Late onset of district nursing did not differ significantly from early onset when amount of care was high. For night nursing care a late onset again increased the likelihood of home death while early onset decreased the likelihood compared to no input. A late onset of Marie Curie nursing increased the likelihood of dying at home. However, an early onset was now no different from no input.

Inclusion of HAH in the analysis did not yield a much improved model compared with one without HAH input, as judged by the percentage of cases correctly classified (82.6% versus 78.9%) and the goodness of fit (318.2 versus 322.1). There were 68.5% of home deaths and 91.5% of inpatient deaths classified correctly.

- Service variables including HAH subdivided on the basis of amount of care

A model based on amount of care (Appendix 2, Table 2.12) appeared to be of less informative value than one based on onset. HAH care was associated with increased likelihood of home death compared to no input, but there was no significant difference between the coefficients for high and low amount of care. A

high amount of HAH care was, however, associated with a significantly higher odds ratio for dying at home compared to merely being referred. The introduction of HAH into an analysis based on amount, did little to change the relationship between district nursing care and home death or amount of hospice care and home death. However, Marie Curie nursing disappeared from the model. Thus there may be a relationship between amount of HAH care and Marie Curie care. The model based on amount classified somewhat fewer cases correctly than one based on onset (78.3%). The reduction in correct classification was in home deaths (56.7%) while that for inpatient deaths remained similar (92.0%). Goodness of fit was, however, better than for the model based on onset of care (291.1).

2.4 CHAPTER 2 SUMMARY AND DISCUSSION

The discussion considers the evidence that HAH was associated with increased likelihood of dying at home. It furthermore assesses the evidence that other home care support was associated with home death. The case mix of the HAH group is reviewed and its implications for the interpretation of the results considered. Current study results are briefly compared to past findings to assess how typical the patient sample may be, and thus whether study findings are generalisable beyond the current context. The discussion concludes with an assessment of the need for an RCT.

2.4.1 Evidence for a relationship between HAH and home death

There are three key point to note in this section. There was a strong association between HAH care and home death. However, it was a late onset of HAH input which showed the strongest association, and HAH referral was in itself associated with home death.

The logistic regression analysis showed that HAH care was the strongest predictor of home death among the variables considered. The positive association between HAH and home death depended on the onset of HAH care, however. A very strong association was found when HAH care began within seven days of death (OR 494, CI 25-9756). The large confidence interval for this odds ratio raises some concern over the

variable's stability (Hosmer and Lemeshow, 1989), but can probably be attributed to the fact that only one patient who began HAH care late died as an inpatient. The removal or addition of only one patient in this cell would therefore change the odds dramatically. Even the lowest value of the confidence interval show considerable odds of dying at home when HAH care began late. In contrast, the positive association between HAH care before the last week of life and home death (OR 7, CI 2-32) was not significantly greater than the association between HAH referral (without HAH admission) and home death (OR 4, CI 2-10). Thus merely being referred to HAH represented an advantage in terms of home death. Furthermore, early introduction to the HAH did not appear to confer an advantage over simply belonging to the group of patients referred to HAH, at least not to an extent which was statistically significant.

Referral to HAH per se should not have an impact on place of death. It does not involve any HAH input. It only means that the patient was considered appropriate for HAH care and was known to the HAH team. It is conceivable that HAH care coordinators attempted to mobilise other support for referred patients who failed to be admitted to HAH, so that referral led to increased home support. While we cannot directly test this, we should note that patients who were merely referred to HAH in fact received less Marie Curie and district nursing compared to those admitted to the service. It is more likely that the positive association between referral to HAH and home death is due to the case mix of referred patients being different to that of the CR sample. Although our analysis in theory should have controlled for any case mix differences, the association between referral and home death suggests that there are other properties of the two patient groups that we have failed to control for. These properties may to a large extent account for the association observed between HAH input and home death. Section 2.4.3 will consider the composition of the HAH group more closely.

The finding that it was late HAH input which was most strongly associated with home death, while early input may be no different from mere referral, may furthermore mean that the association between HAH and home death was mainly a function of place of death, rather than an effect of HAH input. That is, in order to begin HAH care in the last week of life, a patient by definition must have been able to be at home at that point. It may have been the patient's ability to be at home this close to death which accounted for the home

death, not the HAH input. This conclusion is supported by the finding that an early onset of HAH care may not increase likelihood of home death beyond that associated with HAH group case mix. Given our earlier hypothesis that early introduction of care is beneficial, this is somewhat disconcerting. Two points should be taken into consideration here, however. An early introduction of HAH care may also mean that the service had pulled out again closer to death, given its two week limit on care. Early introduction may also imply that the patient required high intensity input for some time before death, and such a situation may have been difficult to sustain at home over a longer period time.

From the present analysis we must conclude that any association between HAH and home death may be due to the case mix of the HAH group in general, and that the relationship between late onset of HAH care and home death may be due to the characteristics of patients able to remain at home so close to death in particular. Patients' ability to remain at home during the last week may be due to their own characteristics, those of their disease, or of their context.

2.4.2 Evidence for a relation between other home care and home death

There was evidence that other home care services than HAH were positively associated with home death. District nursing, Marie Curie and night nursing care were associated with home death independently of any HAH input. There were some changes in the regression coefficients for these services when HAH was introduced into the multivariate analysis. However, overall the previously observed patterns remained, suggesting that there was little interdependence between these services and HAH care.

For night nursing and Marie Curie care the association between service input and home death depended on when care began. Those who began their care close to death (i.e. night nursing within 10 days of death, Marie Curie within 20 days) were more likely to die at home than those who began their care earlier. Simply receiving Marie Curie or night care in itself did not increase likelihood of home death, as earlier onset of these services were not positively associated with death at home. In fact, an early start to night nursing care was associated with decreased likelihood of home death. Thus it is unlikely that the case mix

of patients who accessed these services in general, accounts for any positive association with home death. However, the concern remains that the positive association between late onset of care and home death, may simply mean that patients who were able to remain at home near death received care close to death. Again there does not appear to be any beneficial effect of early introduction of a service. In contrast to HAH which has a two week time limit, early introduction of Marie Curie care or night nursing does not potentially preclude provision of care close to death. Both home services will keep palliative patients in their care for as long as is required. One would therefore have assumed that their early introduction would be positive by enabling bonds and routines to be established and helping the patient and the family prepare for death. However, an early start to care probably signals that patient's need for out of hours care began early, rather than any proactive policy by the service. If the patient begins to require out of hours care at a considerable distance from death, informal (and formal) resources may eventually become exhausted and inpatient admission required. Our Marie Curie and night nursing data may simply mean that patients who are able to be at home close to death and who do not require high intensity input until this point, are more likely to die at home. Again it may be the characteristics of the patients and their disease, rather than the home support, which determines home death.

For district nursing more than twelve hours of input, whether it began early or late (median 101 days from death), was associated with an increase in likelihood of death at home. As this finding does not depend on proximity to death, it may be less likely to be a function of place of death itself, but concerns about case mix differences remain.

We should note that a late onset of hospice inpatient care was negatively associated with death at home. For hospice care late onset (16 days from death), may mainly signal the patient's location close to death. However, a smaller but significantly negative association between early hospice input and home death was also found. This may mean that if an early relationship with the hospice is established, it is more natural to return there for end of life care, or that the length of the patient's palliative care needs point towards inpatient care. A late onset of cardio-thoracic specialist inpatient care (124 days) was also negatively

associated with home death. The time scale makes it more difficult assume it is merely a function of the patient's location close to death.

2.4.3 HAH sample characteristics

So far our discussion has concluded that any association between HAH and home death may partly be due to case mix of patients referred to HAH and partly reflect that patients who are able to be at home close to death are more likely to receive late HAH input. Results may furthermore suggest that patients who have high care needs early on, are less likely to remain at home. This corresponds with other studies of home care patients who are admitted to inpatient care (Groth-Juncker and McCusker, 1983, Hinton, 1994b). Thus any apparent effect of HAH may be attributable to the characteristics of patients, their context and their disease. In this section we consider if the characteristics of the HAH group suggest they are indeed better placed to die at home than other patients, thus supporting our hypothesis that case mix at least in part accounts for the results. An understanding of the characteristics of patients referred to HAH will furthermore help us interpret results of further analyses in Chapters 3 and 4.

The HAH group was younger than the CR group, lived in areas of less social deprivation and were less likely to have been diagnosed within a month of death (Table 2.4). As shown in Chapter 1, these are all factors which have been associated with greater likelihood of dying at home in previous research.

The HAH group was furthermore more likely to have had palliative home care such as Macmillan and Marie Curie nursing, and other community services such as district nursing, night nursing, Flexible care and other community trust primary care, which includes occupational therapy and physiotherapy (Table 2.7). When care was received, the HAH group also had a greater number of hours of district nursing than the CR group. Only for Flexible care did the CR group have more care, in terms of hours of input when care was received. The HAH group was therefore able to draw on more community resources than the CR group. While we are cautious about assuming a causal relationship with home death, it is unlikely that home support is detrimental to death at home.

The HAH group may also have gained access to specialist care more easily. The HAH group was more likely to have had specialist oncology input, and when they had contact with a cardio-thoracic specialist centre, their contact began earlier than that for the CR group (the timing of their contact with oncology was not possible to establish). The HAH group was also more likely to have had hospice inpatient care than the CR group. While hospice care may in the end be negatively associated with home death, a general ability to gain access to specialist palliative care may not be.

Among patients who had care, the CR group began non-palliative community services such as district nursing and other community trust primary care, earlier than the HAH group. If we assume that onset of care is a reflection of when care need begins, our data may imply that the CR patients had had longer term care needs than HAH patients, something which is negatively associated with home death (Cartwright et al, 1973, Groth-Juncker and McCusker, 1983, Hinton, 1994b). However, input over this period may have been at low intensity as reflected by the low number of district nursing hours accumulated by the CR group.

The differences between the HAH and CR group suggests that the HAH group would be better placed to die at home. The logistic regression analysis should, however, in theory be able to control for all these variables. While it may be able to control for the variables we were able to measure, it may not be able to control for the underlying patterns they represent or for factors unknown to us.

One possible underlying pattern is that the cancer of the HAH group may have had a "higher profile" than that of the CR group, whether in its manifestation or in the attention of the specialist services. This may facilitate access to support services in general. The HAH group was more likely than the CR group to have only cancer recorded as the cause of death, which may imply that their cancer was more clearly manifested in the course of illness and symptoms, or that they were more clearly defined as "cancer patients" in light of their past history. A cautionary note is that death certificate differences may also simply reflect different recording practices within different locations of death. The pattern of district nursing care delivery may imply that CR patients often had long term, low dependency needs (perhaps partly associated with their

higher age), while the HAH group may have had shorter term, high dependency needs, whose progress may have been easier to predict and plan for. Although there was no significant difference in diagnosis between the HAH and CR group, the actual course of one and the same cancer can differ greatly (Rinck et al, 1997). This is only one of many possible interpretations, and our data do not enable us to assess its plausibility further. The key point is that our data may signal many potential, underlying patterns, which the logistic regression analysis would not necessarily control for.

One further, important factor that the logistic regression did not control for, is that referral to HAH implies a preference for home care and, probably, home death. Patients, informal carers and their primary health care team must, in theory at least, be in agreement that home care is the preferred option. Past research has shown that patient preference for home death significantly increases the likelihood that the patient will die at home (McWhinney et al, 1995, Karlsen and Addington-Hall, 1998).

In summary, the case mix of the HAH group and their likely preference for palliative home care suggests that these patients may be optimally placed to die at home. This supports our conclusion that the association between HAH and home death may in part be attributed to the case mix of the HAH group. This furthermore has implications for our interpretation of the results of subsequent chapters, in which analysis exclusively relates to patients referred to HAH.

2.4.4 Demographic and clinical variables and home death: issues of generalisability

Results from the present study displays some of the patterns found in previous research in terms of the characteristics of patients referred to home care. Similarly to past research patients referred to HAH were younger, lived in less deprived areas and were more likely to have had specialist oncology care than those not referred. Contrary to previous findings on home care there was no significant difference between the CR and HAH group in terms of overall survival, but the CR group was more likely to have been diagnosed within a month of diagnosis. In contrast to past research no significant relationships were found between referral to HAH and sex, diagnosis, marital status or hospital care. The large number of missing data on

marital status may make the findings for this variable questionable. Whilst the present data do not correspond with that of past research on home care patients in every respect, there are still similarities, i.e. the HAH group does not appear to be unusual in relation to referral to home care.

In terms of place of death our study results differ considerably with previous research, however. There was a notable absence of any effects of demographic and clinical variables on home death. This was probably not because the effects of these variables were masked by service input variables in the multivariate analysis, as a logistic regression including demographic and clinical variables only was performed first. Only two clinical variables showed an association with place of death, number of non-cancer causes of death recorded on the death certificate, and diagnosis within a month of death. The latter has previously been found to relate to place of death (McCusker, 1983, Polissar et al, 1987, Moinpur and Polissar, 1989, Axelsson and Christensen, 1996). Contrary to past research, age, sex, socioeconomic status, type of diagnosis and marital status showed no relationship with place of death. This raises concerns that the study population is atypical, and that the findings in relation to HAH may not be generalisable to hospice at home support in other areas. Higginson et al (1999) show that East Anglia has the highest proportion of home deaths in England (29%), and that the correlations between the Jarman UPA and Townsend ward scores and the proportion of patients dying at home are among the lowest in the country. Thus East Anglia may be unusual in terms of home death. Within this region, the former Cambridge Health District may in turn display unusually high levels of affluence and education.

2.4.5 Observational study summary

A strong relationship between HAH and home death was found. It is therefore clear that the relationship between HAH and death at home merits further investigation. However, within the present study design it was not possible to distinguish between the effect of HAH and that of case mix. The finding that referral to HAH *per se* was positively associated with death at home, suggested that the particular characteristics of the HAH group facilitated home death. Consideration of the case mix of the HAH group suggests that it differed from the comparison group in ways which would probably place them in a better position to die at

home. Although all identified variables which differed between the patient groups should have been controlled for in the logistic regression, there are probably any number of underlying factors for which we failed to control. Furthermore, within the HAH group, it was the patients who began their HAH care in the last week of life who were most likely to die at home. Rather than being attributable to the HAH input, home death may be due to the particular characteristics of the patients or setting which enabled them to be at home so close to death in the first place.

While the observational study was valuable in establishing a link between HAH and home death and in aiding our understanding of the study sample, it did not enable us to disentangle the effects of HAH from that of case mix. In order to pursue the relationship between HAH and home death further we require randomised controlled trial methodology, which will, in theory, remove the effect both of known confounders and that of all unknown confounders.

CHAPTER 3: RANDOMISED CONTROLLED TRIAL

3.1 INTRODUCTION

In the observational study we established that there was a positive association between HAH and home death. However, the research methodology did not allow us to ascertain whether the observed association was due to the service itself or to characteristics of the patients under its care. Randomised controlled trial methodology offers a means of resolving this issue. Given a large enough sample, randomisation of patients to an intervention and a control condition should enable all known and unknown confounding variables to be evenly distributed between conditions. It thereby should ensure that there are no differences between the conditions apart from the intervention itself. Any difference in outcome therefore can be attributed to the intervention.

Palliative care poses particular problems for randomised controlled trials (Grande and Todd, 2000). Two recent reviews (Smeenk et al, 1998, and Rinck et al, 1997) identified eleven RCTs of palliative care interventions, of which only one was in the UK (Addington-Hall et al, 1992, Raftery et al, 1996). Two were unsuccessful and were stopped before the planned sample size was achieved (McWhinney et al, 1994, Rinck et al, 1995) and two included care for the chronically ill as well as palliative care (Zimmer et al, 1985, Weissert et al 1980). Three of these RCTs assessed delivery of chemotherapy treatment (Dodd, 1988, Mor, 1988, Rinck et al, 1995) and one evaluated a counselling service for carers (Toseland, 1995). In addition an RCT of a palliative home care team in Norway has recently been reported (Jordhøy et al, 2000).

Only six of the RCTs specifically considered home care interventions, all versus standard home care (Zimmer et al, 1985, McCorkle et al, 1989, Cummings et al, 1990, Hughes et al, 1992, Addington-Hall et al, 1992, Jordhøy et al, 2000). One of these (Hughes et al, 1992) appears to be a subgroup analysis of Cummings et al (1990). Home care interventions were found to be associated with greater patient satisfaction (Cummings et al, 1990, Hughes at al, 1992) and cost effectiveness (Raftery et al, 1996), and a decrease in symptoms and social dependency (McCorkle et al, 1989). A negative result for home care was

found in only one trial, in which patient perceptions of own health was worse in the home care group than the control group (McCorkle et al, 1989). Only two RCTs investigated place of death (Zimmer et al, 1985, Jordhøy et al, 2000). Zimmer et al (1985) investigated the effects of a home care team consisting of a nurse, physician and social worker providing home visits and a 24 hour telephone service. Although more patients in the intervention than control group died at home, consideration of the numbers suggests this result was not significant (Chapter 1). Furthermore more control than intervention group patients were lost to follow up and only a quarter of patients enrolled had died by the end of the study, potentially introducing bias. For instance, it may have been more difficult to follow up control patients who died in the community rather than in hospital, and the distribution of place of death may have been different for patients who died early, i.e. within the study time frame, rather than later. Jordhøy et al (2000) considered an outreach team operating during daytime hours, and consisting of two palliative care nurses, a physician, social worker, chaplain, nutritionist and physiotherapist. This study used cluster randomisation with only six clusters, and characteristics of intervention patients were significantly different from controls. Logistic regression analysis was employed to attempt to control for potentially confounding variables, and this analysis showed the control group to be only marginally, although significantly, less likely to die at home.

The low number of successful trials probably bears witness to the particular difficulties associated with conducting RCTs in palliative care. Sample attrition, ethical concerns around randomising vulnerable patients to treatments and subjecting them to research in general, the often unpredictable course of illness, and patients' and carers' frequent inability to complete measures, all combine to make RCTs difficult within this field (McWhinney et al, 1994, Grande et al, 1999, Grande and Todd, 2000).

Bearing these issues in mind, it was nevertheless believed that most of these problems could be overcome in the present study. There was close cooperation between the research team and the HAH service, and initial estimates of patient numbers suggested that sufficient power could be attained within the trial period. As HAH could not accommodate all patients referred, randomisation was perceived to be an acceptable means of allocating patients to the limited number of spaces available. It therefore formed an integral part of the HAH referral procedure. Professional groups likely to refer to HAH, including hospital community

care planning team (CCPT) members, GPs, district nurses and Macmillan nurses, had received written information about the trial. The researcher furthermore provided trial information and updates in person to the district nurse professional development group and the hospital CCPT, as these represented the key sources of referral. In addition to place of death, the trial aimed to collect patient and carer self report measures as part of a broader evaluation of HAH (Grande et al, 1998, Grande et al, 2000), and there was cautious optimism that sufficient self report data could be collected for analysis. A complete data set could be expected for place of death, the outcome measure relevant to this thesis.

3.2 METHOD

3.2.1 Patient samples

The observational study compared patients referred to HAH with a similar sample of patients not referred to HAH. In contrast, the RCT only incorporated patients who were referred to HAH. The observational study showed that the characteristics of patients referred to HAH were different from the rest of the palliative patient population. Patients referred to HAH may already be optimally placed to die at home. The nature of the patient sample needs to be considered when interpreting the results of the RCT.

In the observational study the patient samples were limited to cancer patients who had died from their cancer. This decision was based on the need to find a sensible comparison sample for the patients referred to HAH. The cancer patients represented a relatively homogenous group compared to the non-cancer patients, and one for which the Cancer Registry could provide a comprehensive comparison group sampling frame. In contrast, it would have been more difficult to find a comparison sample for the 26 non-cancer patients of various diagnosis who were referred to HAH. The RCT does not pose similar problems in that the comparison sample is derived from the randomisation procedure itself. We therefore chose to include non-cancer patients in the analysis of the RCT. Due to the inclusion of non-cancer patients (14% of the patient sample) the case mix for patients entering the RCT is likely to be similar but not identical to that of patients referred to HAH in the previous section.

Participants were consecutive referrals to HAH over a fifteen month period. As outlined in Chapter 1, section 1.4.1, adult Cambridge Health District residents of all diagnoses could be referred for terminal care (last two weeks of life), and patients with cancer, MND and AIDS could be referred for palliative care at any point. A referral to HAH implied that home care was preferred by the patient.

3.2.2 Randomisation procedure

The randomisation sequence was generated from a statistical table of random numbers and concealed in sequentially numbered, opaque, sealed envelopes. Upon referral the HAH coordinator opened the sealed envelope, which identified the allocation of the patient, and informed the person making the referral whether the patient was to receive HAH or be a control. It was not possible to blind recipients or health professionals to the fact that the patient received the HAH intervention.

In rare circumstances a patient could be assigned to HAH without randomisation and thus fail to enter the randomised controlled trial: 1) if referred when HAH was "empty" the patient would be admitted to ensure HAH places were filled; 2) if referred as an emergency when no standard care was available, HAH would be provided as a stopgap.

3.2.3 Interventions

Both patients allocated to HAH and controls could receive the standard care services provided in the district. However, the intervention group could in addition receive HAH. Thus the trial compared HAH and standard care with standard care only. Standard care comprised care in hospital or hospice, or care at home with input from general practice, district nursing, Marie Curie nursing, Macmillan nursing, night nursing, Social Services, Flexible Care nursing, other community trust primary care or private care as described in Chapter 1.

3.2.4 Statistical power

HAH was funded to accommodate approximately 100 patients per year with referrals expected at twice this rate. This would have made possible a 1:1 random allocation of 180 patients to each RCT trial arm over a 22 month period. This would have yielded 80% power to detect a 15% difference (50-65%) in numbers of patients dying at home at $\alpha = 0.05$. The observational study period confirmed a referral rate of approximately 200 per annum and an admission rate of approximately 100 per annum. However, it became clear from the observational study that many patients referred to HAH failed to obtain the service, due to the particular problems associated with the patient group. These included deterioration and death occurring shortly after referral, or other unexpected changes in circumstance (e.g. urgent inpatient admission for symptom control, carer becoming unable to cope at home). Failure to obtain HAH was rarely due to a lack of HAH resources. Thus to allow for attrition and ensure that HAH places were filled, the randomisation ratio was set at 4:1 of HAH to standard care. Ensuring that HAH operated at full capacity at all times, was important in gaining cooperation from health professionals, thus allowing the trial to be conducted. *Requiring a health service to operate below capacity when the resources were available would also be* ethically questionable. As part of the broader evaluation of the HAH service the trial also aimed to collect self report measures from patients and family carers. However, an initial trial period showed that only approximately 30% of patients were able to complete measures, even with help and after measures had been greatly simplified (Grande, 1996). Data collection was therefore changed to a retrospective survey of GPs, district nurses and informal carer, conducted within six weeks of the patients death (details and results reported in Grande et al, 2000). The need to change the data collection strategy resulted in the trial period being reduced from 22 to 15 months. Changes in design overall implied a considerable reduction in statistical power, as only 200 HAH patients and 50 controls could now be expected to enter the trial. Thus the trial could not overcome the problems common to RCTs in palliative care quite to the extent initially hoped. Nevertheless, a trial could be carried out following adjustments to the study protocol. The patient numbers actually obtained would have given 80% power to detect a 24% difference (50%-74%) between the control and intervention group in home deaths at $\alpha = 0.05$, a difference which did not seem implausible

given the difference between patient referred to HAH who were and were not admitted to HAH in the observational study (Table 2.2).

3.2.5 Data collection

Additional information from HAH records was available for the RCT compared to the observational study. This included whether the patient was living alone, whether there was a next of kin, and the relationship between the patient and the person identified as next of kin. Diagnosis, location at referral to HAH and referral date were also recorded. Date of referral and date of death were used to calculate survival following referral.

In the RCT diagnosis recorded at HAH referral was used rather than East Anglian Cancer Registry (EACR) diagnosis, as many of the RCT sample patients did not have cancer. The date of EACR cancer diagnosis was, however, used to calculate survival from diagnosis for patients who were on the registry.

Otherwise variables considered in the RCT analysis were identical to those considered in the observational study. These were cause of death, survival from diagnosis, age, sex, socioeconomic area of residence, social class as defined by occupation, and characteristics of the primary health care team. Secondary and tertiary service variables were contact with oncology specialist services, acute hospital inpatient, outpatient and day care, hospice inpatient care, cardio-thoracic specialist inpatient care and continuing care bed input. Community care services considered alongside HAH were district nursing, night nursing, Macmillan nursing, Marie Curie nursing, Flexible care and other community trust primary care. Observational study Section 2.2.3 gives the details for the sources of these data. In the RCT electronic record data were collected by the researcher rather than the computer assistant.

3.2.6 Data preparation

Diagnosis was based on HAH record entries, in which diagnosis was entered as free text. In the majority of cases, it was clear what the patient's diagnosis was perceived to be. For some cases a decision had to be made regarding coding. An entry of "cerebral tumour" was coded as a CNS cancer (3 cases). When a diagnosis was entered with a question mark alongside it (3 cases), the diagnosis was entered, as this was still considered the best guide to the patient's illness. When the location of secondaries only was recorded, or terms such as carcinomatosis, "inoperable" or "undiagnosed tumour", or "abdominal mass" were used, the cancer was coded as ICD10 C76-C80 ("Malignant neoplasms of ill defined, secondary or unspecified sites", 13 cases). For patients with multiple diagnoses (9 cases) and for cases for which only "cancer" was recorded (3 cases), the cause of death on the death certificate was used as a guide. Chest infections (2 cases) were coded as pneumonia, and cardiac problems or cardiac failure (3 cases) as circulatory disease, in accord with the death certificate. This coding strategy may have given a closer correspondence with the death certificate cause of death than was warranted. However, these cases represent a relatively small proportion of the overall patient group and any inaccuracies should be evenly distributed between the control and HAH condition.

For all other variables data preparation was conducted using the same procedures as for the observational study (see observational study section 2.2.4 for details). In the RCT the service input data were prepared by the researcher rather than the computer assistant, but following the procedures developed by the computer assistant.

3.2.7 Analysis and statistical tests

The characteristics of the control group and intervention groups were compared first to assess whether there were indeed no measurable differences between the two groups apart from the intervention itself. The randomisation procedure should ensure that there were no systematic demographic or clinical differences between the control and intervention groups. For these variables the sample analysis serves to ascertain

whether the randomisation has really worked in distributing these variables equally between the arms of the trial. For service input variables, however, the outcome of the randomisation could conceivably influence subsequent service use. Admission to HAH may lead to easier access to services such as Marie Curie. Alternatively, allocation to the control condition may lead to efforts to bring in other services to compensate for absence of HAH. While differences in service input prior to HAH referral should be evenly distributed between groups through randomisation, systematic group differences subsequent to referral may still have occurred.

Next an intention to treat analysis was performed with place of death as the outcome variable, i.e. the control and intervention group were compared, irrespective of whether they received their allocated treatment (Hollis and Campbell, 1999). This serves to preserve the benefits of randomisation, ensuring that the only systematic difference that remains between groups is the intervention itself, with all other potential confounders at least in theory equally distributed between groups. Conversely, bias is likely to be introduced if analysis focuses only on patients who actually received an intervention. These may be, for instance, patients who particularly preferred the intervention, were most likely to benefit from it, or possibly in our case, patients who were likely to die at home anyway. In these cases clinical effectiveness may be overestimated if an intention to treat analysis is not performed. Furthermore, intention to treat is likely to give a pragmatic estimate of the benefits of a service, as services in real life are unlikely to be able to fully cater for all those for whom their care is intended (Hollis and Campbell, 1999).

In the observational study many patients referred to HAH failed to be admitted to the service. It was initially assumed that this problem would be greatly reduced in the RCT, as many of the patients referred to HAH would be randomised to a control group, thus reducing the number of HAH patients to be accommodated. However, while the HAH admission rate was higher in the RCT than in the observational study, many patients randomised to HAH still failed to receive HAH care. Analysis was nevertheless conducted in accord with patients' allocated group membership. The only patients excluded from this analysis were those still alive at the end of the study for whom place of death was not available.

Treatment of service variables and statistical tests for comparison of patient groups were the same as those of the observational study (Chapter 2, section 2.2.5).

3.3 RANDOMISED CONTROLLED TRIAL RESULTS

In the following sections the patient recruitment numbers are reported first, data on HAH admission and diagnosis from HAH records are compared with data from other sources, the characteristics of patients allocated to HAH and the control condition are reported, and finally the results of the RCT intention to treat analysis are presented in relation to the primary outcome variable, i.e. place of death.

3.3.1 Size of recruited patient samples

Of 262 patients referred, 21 (8%) were not randomised and therefore did not enter the trial, due to low HAH activity or "emergency" referrals (see 3.2.2). Of the 241 patients randomised, 12 patients were still alive at the end of the study, and did therefore not enter analysis. Data were collected for the remaining 43 control patients and 186 patients allocated to HAH. Of the patients allocated to HAH, 113 (61%) were admitted to the service according to HAH records. Of the patients who entered the trial there were 115 (50.2%) females and 114 (49.8%) males. Mean age was 72.2 (s.d. 13.0). Further details on patient characteristics are provided in sections 3.3.3 and 4.3.2 of the thesis.

3.3.2 Verification of HAH record data

- HAH admission

Table 3.1 compares HAH admission according to HAH records and electronic record linkage data. The comparison yielded a Kappa value of 0.834, indicative of almost perfect agreement (Landis and Koch, 1977). "No HAH input" includes control patients and patients allocated to HAH but not admitted to the service.

Table 3.1: *Comparison of HAH record and record linkage accounts of number of patients who received HAH input*

	HAH records	
Record linkage:	No HAH input	HAH input
No HAH input	105 (90.5%)	8 (7.1%)
HAH input	11 (9.5%)	105 (92.9%)

Whilst the record linkage data showed three of the controls to have had HAH input, this did not represent a large amount of input: the three patients had two and a half, nine and thirteen HAH hours recorded respectively. As electronic data on HAH and Marie Curie nursing hours were entered on the same database, this recorded input may have resulted from an error in the entry code for the type of nursing service provided. Similarly to the observational study, HAH's own records were used to decide which patients were admitted to the HAH service.

- *HAH cancer diagnosis*

Of 216 patients who had cancer according to HAH records, 204 were located on the East Anglian Cancer Registry (EACR) and 202 of these had cancer recorded as a cause of death on the death certificate. Of the 12 patients who were not found on the EACR, nine nevertheless had cancer recorded as a cause of death. Thus for 213 of the 216 patients recorded with cancer on the HAH records, there was confirmation of the cancer diagnosis in the form of EACR entry and/or as recorded cause of death on the death certificate.

Of the 33 non-cancer patients recorded in the HAH records, 30 were not found on the EACR. These 30 had only non-cancer causes of death on their death certificate. The remaining three patients did have an EACR entry, but one of them had only non-cancer causes of death recorded on the death certificate. Cancer was therefore implicated in the death of two of the 33 patients recorded with a non-cancer diagnosis on the HAH records. There is thus a close, although not perfect relationship between cancer and non-cancer diagnosis as recorded on HAH records and the evidence presented by EACR records and death certificates.

3.3.3 Comparing control patients with patients allocated to HAH

In this section patients allocated to the control and HAH condition are referred to as the control and HAH group respectively. Patients within the HAH group who had HAH input recorded received a median of 52.3 hours (i.q.r. 112.3) of care and began their HAH care a median of 12 days (i.q.r. 38) before death.

- HAH referral details

The control and HAH group did not differ in terms of location at referral (home or inpatient) and survival following referral (Table 3.2).

Table 3.2: Referral details. Control group n=43, HAH group n=186.

	Controls	HAH group	Significance level
Location at referral:	**n (%)**	**n (%)**	
Home	30 (69.8)	127 (68.3)	
Inpatient care	13 (30.2)	59 (31.7)	X^2=0.000, d.f.=1, p=0.994
Survival after referral	**Median (i.q.r.)**	**Median (i.q.r.)**	
Days	11 (23)	11 (30)	Z=0.604, p=0.546

- Demographic and clinical variables

The control and HAH group did not differ in terms of percentages of patients living alone or person recorded as next of kin on HAH records (Table 3.3).

Table 3.3: Informal support; n recorded in table.

	Control group	HAH group	Significance level
Living alone:	**n (%)**	**n (%)**	
Yes	7 (17.1)	39 (21.4)	
No	34 (82.9)	143 (78.6)	X^2=0.167, d.f.=1, p=0.683
Next of kin:			
Husband	15 (34.9)	46 (24.7)	
Wife	17 (39.5)	70 (37.6)	
Son	3 (7.0)	15 (8.1)	
Daughter	4 (9.3)	33 (17.7)	
Other[1] or none recorded	4 (9.3)	22 (11.8)	X^2=3.173, d.f.=4, p=0.529

[1]Other: siblings, daughters in law, nieces, grandchildren, parents (12 cases) and friends, a landlady and a lodger (7 cases).

For next of kin the categories "Other" and "None recorded" were combined to avoid violating the assumptions of the X^2 test (Siegel and Castellan, 1991). Appendix 3, Table 3.1 shows the patient numbers with "Other" and "None recorded" separated.

There were no significant differences between the control and HAH group in terms of cause of death, survival, diagnosis, age, sex or socioeconomic variables (Table 3.4). Due to low numbers some diagnosis categories had to be collapsed for statistical analysis (Siegel and Castellan, 1991). CNS, haematological and head/neck cancers were grouped with "Cancer other". Non-cancer diagnoses were grouped into one non-cancer category. Appendix 3, Table 3.2 shows the full diagnosis details.

There were no significant differences between the control and HAH group in terms of any of the measured primary health care team characteristics (Table 3.5).

Table 3.4: Causes of death, survival, diagnosis, age, sex and socioeconomic status (control group n=43, HAH group n=186 unless otherwise indicated)

	Control group	HAH group	
CAUSE(S) OF DEATH:	**n (%)**	**n (%)**	
Only cancer cause(s)	32 (74.4)	124 (66.7)	
Both cancer and non-cancer causes	5 (11.6)	34 (18.3)	
Only non-cancer cause(s)	6 (14.0)	28 (15.1)	$0X^2$=1.244, d.f.=2, p=0.537
SURVIVAL:	**Median (i.q.r) (n=36)**	**Median (i.q.r.) (n=154)**	
Survival from diagnosis (days)	417 (840)	300 (894)	Log Rank statistic=0.26, d.f.=1, p=0.609
Diagnosis within a month of death.	**n (%)**	**n (%)**	
Yes	3 (8.3)	9 (5.8)	
No	33 (91.7)	145 (94.2)	Fisher exact test, p=0.702
DIAGNOSIS			
Cancer			
Breast	4 (9.3)	14 (7.5)	
Gastrointestinal	5 (11.6)	43 (23.1)	
Genitourinary	13 (30.2)	32 (17.2)	
Lung	7 (16.3)	16 (8.6)	
Cancer other	8 (18.6)	54 (29.0)	
Non-cancer	6 (14.0)	27 (14.5)	X^2=8.817, d.f.=5, p=0.117
AGE:	**Mean (s.d.) (n=43)**	**Mean (s.d.) (n=184)**	
	72.1 (11.3)	72.3 (13.4)	t=0.06, d.f.=225, p=0.950
SEX:	**n (%)**	**n (%)**	
Females	23 (53.5)	92 (49.5)	
Males	20 (46.5)	94 (50.5)	X^2=0.094, d.f.=1, p=0.759
SOCIOECONOMIC AREA:	**Median (quartiles)**	**Median (quartiles)**	
Jarman UPA score.	0.198 (18.289)	-0.941 (21.697)	Z=0.848, p=0.396
Townsend index.	-0.243 (4.019)	-0.800 (3.889)	Z=0.968, p=0.333
SOCIAL CLASS:	**n (%) (n=43)**	**n (%) (n=177)**	
I	4 (9.3)	22 (12.4)	
II	10 (23.3)	40 (22.6)	
IIIN	2 (4.7)	21 (11.9)	
IIIM	17 (39.5)	46 (26.0)	
IV	9 (20.9)	40 (22.6)	
V	1 (2.3)	8 (4.5)	X^2=4.682, d.f.=5, 0.456

Table 3.5: GP and district nurse characteristics

	Control group	HAH group	Significance levels
GP LIST SIZES	**Median (i.q.r.)** (n=42)	**Median (i.q.r.)** (n=170)	
GP total list size	1952.5 (554)	1874 (561.3)	Z=1.320, p=0.187
List size aged 65-74	133.5 (116.3)	129.5 (106.5)	Z=0.617, p=0.537
List size aged > 75	121.5 (97.3)	122 (97.3)	Z=0.538, p=0.591
Proportion of rural patients	0.230 (0.467)	0.179 (0.350)	Z=0.221, p=0.825
GP PRACTICE CHARACTERISTICS	**Median (i.q.r)** (n=43)	**Median (i.q.r)** (n=186)	Z=0.859, p=0.391
Number of partners	5 (2)	5 (2)	
Training practice:	**n (%)**	**n (%)**	
Yes	29 (69.0)	104 (56.5)	
No	13 (31.0)	80 (43.5)	X^2=1.728, d.f.=1, p=0.189
Fundholding practice:	**n (%)**	**n (%)**	
Yes	14 (33.3)	41 (22.3)	
No	28 (66.7)	143 (77.7)	X^2=1.707, d.f.=1, p=0.191
DISTRICT NURSE TEAM			
Team based at surgery:	**n (%)**	**n (%)**	
Yes	30 (73.2)	115 (63.5)	
No	11 (26.8)	66 (36.5)	X^2=0.977, d.f.=1 , p=0.323
Team size:	**Median (i.q.r)** 4 (2)	**Median (i.q.r.)** 4 (2)	Z=1.055, p=0.291
DN sisters and RGNs in team:	2 (2)	2 (2)	Z=0.199, p=0.842

- NHS service input

Table 3.6 shows Cancer Registry records of contact with hospital and oncology specialist services during the course of the patient's illness. There were no differences between groups on these measures.

Table 3.6: Percentage of patients recorded on the Cancer Registry to have been in contact with a hospital or with a hospital oncology department.

	Controls n (%)	HAH group n (%)	Significance level
In contact with hospital:			
Yes	36 (100.0)	152 (98.7)	
No	0 (0.0)	2 (1.3)	Fisher exact test: p=1.000
In contact with an oncology department:			
Yes	22 (61.1)	70 (45.5)	
No	14 (38.9)	84 (54.5)	X^2=2.271, d.f.=1, p=0.132

There were no differences between the control and HAH group in proportion of patients who had contact with other NHS services during their last year of life (Table 3.7).

Table 3.7: Number (percentage) of patients who received a service in their last year of life

	Controls	HAH group	Significance level
Acute hospital inpatient	29 (67.4)	108 (58.1)	X^2= 0.917, d.f.=1, p=0.338
Acute hospital daycase	11 (25.6)	37 (19.9)	X^2= 0.382, d.f.=1, p=0.536
Acute hospital outpatient appt[1]	29 (67.4)	125 (67.2)	X^2= 0.000, d.f.=1, p=1.000
Hospice inpatient	12 (27.9)	67 (36.0)	X^2=0.690 , d.f.=1, p=0.406
Continuing care beds	1 (2.3)	11 (5.9)	Fisher's Exact Test, p=0.472
Cardio-thoracic specialist inpatient	5 (11.6)	11 (5.9)	X^2=0.986 , d.f.=1, p=0.321
District nursing	36 (83.7)	165 (88.7)	X^2= 0.412, d.f.=1, p=0.521
Night nursing	9 (20.9)	43 (23.1)	X^2= 0.011, d.f.=1, p=0.915
Macmillan nursing	17 (39.5)	51 (27.5)	X^2= 1.910, d.f.=1, p=0.167
Marie Curie	21 (48.8)	98 (52.7)	X^2= 0.082, d.f.=1, p=0.775
Other community trust care	9 (20.9)	45 (24.2)	X^2= 0.065, d.f.=1, p=0.799
Flexible care	11 (25.6)	34 (18.3)	X^2= 0.762, d.f.=1, p=0.383

Among patients who received care there were no significant difference between the control and HAH groups in amount of input recorded (Table 3.8).

Table 3.8: Amount of input per patient in the last year of life for those patients who had a service. Median (quartiles). Mann-Whitney U-tests used for comparison.

	Controls	n	HAH group	N	Significance level
Acute hospital inpatient days	16 (10, 34)	29	18.5 (11.5, 36.5)	108	Z=0.343, p=0.732
Acute hospital daycase appointment	1 (1,6)	11	2 (1,4)	37	Z=0.013, p=0.990
Acute hospital outpatient appointments[1]	5 (3,11)	29	5 (3,10)	125	Z=0.141, p=0.887
Hospice inpatient days	13 (9, 26.5)	12	16 (8, 28)	67	Z=0.007, p=0.995
Continuing care bed days	150	1	30 (23, 39)	11	Z=1.596, p=0.110
Cardio-thoracic specialist inpatient days	4 (2,13)	5	11 (4.5, 18)	11	Z=0.852, p=0.394
District nursing hours	20.0 (9.7, 37.4)	36	20.7 (11.9, 45.1)	165	Z=0.574, p=0.566
Night nursing hours	6.3 (1.5, 16.1)	9	2.7 (1.3, 5.9)	43	Z=1.428, p=0.153
Macmillan nursing hours	1.5 (1.2, 4.3)	17	2.6 (1.5, 4.5)	51	Z=0.866, p=0.387
Marie Curie nursing hours	51 (22.5, 126)	21	33.8 (13.5, 82.3)	98	Z=1.315, p=0.188
Other community trust hours	1.2 (0.8)	9	1.5 (0.8, 2.1)	45	Z=0.558, p=0.577
Flexible care hours	23.5 (8.3, 34.1)	11	11 (6.2, 49.0)	34	Z=0.000, p=1.000

Among patients who received care, there were no significant differences between the control and HAH groups in terms of onset of other NHS care (Table 3.9).

Table 3.9: Onset of care for those patients who received a service. Days before death. Median (quartiles).

	Control	n	HAH group	n	Significance level
Acute hospital inpatient	175 (65, 275)	29	162 (77.5, 292)	108	Z=0.129, p=0.897
Acute hospital daycase	193 (156 , 238)	11	206 (127, 294)	37	Z=0.221, p=0.825
Hospice inpatient	26.5 (11, 82)	12	51 (17, 102)	67	Z=0.615, p=0.539
Continuing care beds	239	1	77 (36, 238)	11	Z=0.726, p=0.468
Cardio-thoracic specialist inpatient	89 (78, 95)	5	251 (120.5, 342.5)	11	Z=1.757, p=0.079
District nursing	108 (59, 261.5)	36	180 (58, 317)	165	Z=1.257, p=0.209
Night nursing	22 (10, 37)	9	11 (4.5, 41)	43	Z=0.714, p=0.475
Macmillan nursing	80 (19, 178)	17	82 (36.5, 161.5)	51	Z=0.453, p=0.650
Marie Curie nursing	22 (6, 46)	21	27 (8, 68)	98	Z=0.377, p=0.707
Other community trust care	32 (15, 41)	9	81 (38, 142)	45	Z=1.532, p=0.126
Flexible care	21 (9.5, 54)	11	49 (14, 116)	34	Z=0.991, p=0.322

3.3.4 Place of death for HAH and control group

When comparing patients randomly allocated to the control and HAH condition, no significant differences were found in terms of demographic, clinical or service input variables. There were therefore no differences between the control and HAH group apart from the intervention itself at $p<0.05$. Only one difference achieved $p<0.1$, timing of onset of cardio-thoracic specialist inpatient care. Any difference in place of death between the two groups can therefore with some confidence be attributed to HAH.

Table 3.10 shows the place of death for patients allocated to the control and HAH group in the RCT.

Table 3.10: Place of death for patients allocated to the control and HAH group

	Control group n (%)	HAH group n (%)	Significance level
Death at home	25 (58.1)	124 (66.7)	
Death in inpatient care	18 (41.9)	62 (33.3)	X^2=0.774, d.f.=1, p=0.379

A higher percentage of the HAH group (67%) died at home than the control group (58%). However, this difference was not significant. Thus the patients allocated to HAH were not more likely to die at home than controls.

3.4 CHAPTER 3 SUMMARY AND DISCUSSION

There were no significant differences between the control and HAH groups on any variable apart from the intervention itself. While the randomisation procedure should distribute evenly any demographic or clinical variables and any service input occurring before referral, some concern was expressed that allocation to a trial arm may influence subsequent service input. However, there was no evidence that allocation to control or HAH group had any impact on other service use.

There was no significant difference in home death between the HAH and control group. The RCT evidence therefore suggests that HAH had no impact on place of death.

Two methodological problems, however, raise concerns that the RCT was not fully able to answer our question of whether HAH had an impact on place of death. The first relate to failure to attain sufficient statistical power, the second to the dilution of the treatment effect.

Two factors contributed to the failure of attaining sufficient statistical power: the unequal randomisation ratio of 4:1 and the limited time available for the study. Instead of the planned 1:1 randomisation ratio, a 4:1 ratio of HAH to control was set because many of the patients allocated to hospital at home did not receive the service. Far more patients therefore had to be allocated to hospital at home than to the control condition to ensure that the service ran at or near capacity. In addition 8% of suitable patients had to be excluded from the study to fill HAH spaces during quiet periods and accommodate emergency referrals. Had we not compromised in this way, the trial would have prevented the service from reaching as many patients as its resources permitted. This would probably have resulted in reduced cooperation from health professionals and the likely collapse of the trial, as well as raised ethical concerns.

Given that randomisation was justified on the basis of resource limitations, the randomisation ratio could only have been improved by increasing the rate of HAH admissions among those allocated to the service or by increasing the referral rate. Failure to admit patients to HAH was mainly due to the unpredictable

change in circumstances often associated with palliative care, including rapid deterioration and urgent inpatient admissions. Ability to respond more rapidly and command of more resources may have allowed HAH to increase its admissions to some extent. However, this would have required a considerably higher investment in the service. An increase in referrals would have allowed the trial to shift the surplus of patients over to the control condition, and to this end encouragement was given to health professionals to refer more patients. However, there is probably a limit to how much referrals could increase, particularly if an increase in referrals meant decreased likelihood of obtaining an admission.

Given the randomisation ratio set for the study, 450 HAH patients and 110 controls would have had to enter the trial to achieve the planned statistical power (80% power to detect a 15% difference). This would have required the trial to be extended from 15 to 34 months. This was not possible within the time limits for the HAH evaluation. An extended pilot period was necessary to allow the service to undergo several changes and settle down into its final form. A proper understanding of referral and admission patterns was essential to arrive at a feasible trial design. The need to finally abandon prospective data collection due to data attrition and switch to retrospective collection of process measures, led to further time reduction (Grande et al, 2000). The hospital at home service itself was only funded for a limited period, its future funding in part dependent on the outcome of the trial. The trial therefore needed to be completed and the results analysed in time to inform this process.

The failure to admit patients to HAH which caused the unfavourable randomisation ratio, also led to a considerable dilution of the treatment effect, thus further reducing the likelihood of observing an impact of the service. Only 61% of patients allocated to hospital at home obtained the service. This is a problem common in palliative care evaluation (McWhinney et al, 1994). The analysis still remained intention to treat, and patients were analysed in accord with their allocated group membership without changes or omissions (Hollis and Campbell, 1999), thus ensuring that there were no systematic differences between trial arms.

These difficulties raise the question whether the RCT is a suitable methodology for palliative care evaluations. This issue will be considered further in the final chapter. In the current study it was decided that an analysis of the relationship between actual HAH input and home death should be conducted, given that the percentage of home deaths observed in the HAH group was higher than in the control group, and that there was considerable loss of power and dilution of the treatment effect. This analysis is the subject for the next chapter.

CHAPTER 4: ANALYSIS OF ACTUAL HAH TREATMENT AND PLACE OF DEATH

4.1 INTRODUCTION

The randomised controlled trial intention to treat analysis showed no significant impact of HAH on place of death. However, because of the loss of power in the trial and dilution of the treatment effect, some doubt remains whether the trial did resolve our central question. The concern is that we may have retained the null hypothesis (HAH has no effect on home death) when it was in fact false (Type II error), i.e. HAH did have an effect which we failed to detect due to problems of the research design. The rationale for the analysis in this chapter is that by considering actual HAH treatment rather than intention to treat, we are more likely to detect any association between HAH care and the outcome variable, home death.

However, as noted in Chapter 3, when considering actual treatment rather than intention to treat, there may be systematic differences between the comparison groups. Patients admitted to HAH are likely to be different from those not admitted to the service. The analysis in the previous chapter showed there to be no significant differences between the RCT control and intervention group. However, RCT intervention group patients who were admitted to HAH are likely to be different from intervention group patients not admitted, in a similar manner that observational study patients admitted to HAH were different from those referred but not admitted. We can partly counteract this problem by using multivariate logistic regression analysis to control for any variables found to differ between groups, which may be confounders. However, while RCT methodology should remove the effect of both known and unknown variables by equally distributing them between groups, the logistic regression analysis cannot control for unknown variables, and we cannot be certain that the effect of case mix on the outcome variable is fully removed. This is the same problem which faced us in the observational study.

Nevertheless, there are likely to be fewer case mix differences in the analysis of the RCT sample than in the observational study. The RCT sample would be more homogenous (in spite of the inclusion of a small proportion of non-cancer patients), because it only consists of patients referred to HAH. If the association

between HAH and place of death is greatly reduced as the sample becomes more homogenous, this implies that the strong association between HAH and home death in the observational study was largely attributable to case mix. If the relationship between HAH and home death remains strong, however, we can be more confident that we are observing a genuine effect of HAH itself, although an effect of case mix can not be discounted.

This chapter first explores the relationship between actual HAH input and home death using univariate analysis. Next a mulitvariate logistic regression of this relationship is conducted, following identification of potentially confounding variables which need to be controlled for.

4.2 METHOD

Data collection and preparation were as described in the previous chapter.

4.2.1 Patient samples

The 229 patients who entered the RCT and are described in the previous chapter, also formed the basis for the analysis in the present chapter.

4.2.2 Analysis and statistical tests

The sequence of analysis, statistical tests, treatment of service variables and method of logistic regression were the same as for the observational study (Chapter 2, sections 2.2.5 and 2.3.7). As before, a lax criterion of $p<0.2$ was used to identify variables for entry into the logistic regression (Altman, 1990).

The relationship between actual HAH input and home death is first explored through univariate analysis (Section 4.3.1). Next, to identify variables to be controlled for in the logistic regression analysis, intervention patients admitted to HAH are compared with intervention patients not admitted to HAH

(Section 4.3.2). Section 4.3.3 summarises the variables to be considered for the logistic regression, while section 4.3.4 describes the preparation of the service input variables for analysis. The sequence and rationale for the subsequent logistic regression analyses are the same as that of the observational study. First, a logistic regression of demographic and clinical variables only is conducted (Section 4.3.5) to assess the extent to which these variables on their own have a bearing on place of death. Second, service input variables are considered alongside the demographic and clinical variables (Section 4.3.6) to investigate the extent to which all variables apart from HAH can predict place of death, and to assess any interrelationships between service variables and demographic and clinical variables. Finally, HAH input will be entered alongside all the other variables, and its relationship with place of death and effect on other variables in the model observed (Section 4.3.7).

4.3 RESULTS

4.3.1 Univariate analysis of HAH and place of death

The following analysis uses HAH admission as defined by HAH records (Chapter 3, Table 3.1). It compares patients who had HAH input (intervention patients who received HAH) with patients who had no HAH input (control patients and intervention patients who failed to receive HAH).

Table 4.1: HAH input by place of death

	Patients with no HAH input (n=116) n (%)	Patients with HAH input (n=113) n (%)	Significance level
Home death	61 (52.6)	88 (77.9)	
Inpatient death	55 (47.4)	25 (22.1)	X^2=15.013, d.f.=1, p<0.001

Table 4.1 shows that patients who had HAH input were significantly more likely to die at home compared to patients who had no HAH input. Comparison with patients who were referred to HAH in the observational study, show a lower proportion of home deaths among RCT patients who had HAH input (78%) than among observational study patients who had HAH input (86%). Conversely, RCT patients who

had no HAH input had a higher percentage of home deaths (53%) than observational study patients who were referred to HAH but not admitted to the service (44%)(Table 2.2, Chapter 2).

A closer scrutiny of the RCT patients who had no HAH input (Table 4.1) show that there was no significant difference in proportion of home deaths between the RCT control patients (58%) and the intervention patients who failed to receive HAH (49%) (X^2=0.528, d.f.=1, p=0.457). If anything, fewer of the intervention patients appeared to die at home than the controls. Merely being allocated to HAH (and not admitted) clearly did not confer any advantage in terms of dying at home.

To further explore association between HAH and home death, Table 4.2 compares amount and onset of HAH care between patients who died at home and in inpatient care.

Table 4.2: Amount and onset of HAH input by place of death, patients who were admitted to HAH only

	Amount of HAH care (hours) Median (i.q.r.)	**Onset of HAH care (days before death) Median (i.q.r.)**
Home death (n=88)	53.25 (126.11)	7.5 (27.0)
***Inpatient death* (n=25)**	28.00 (100.48)	31.0 (74.5)
Significance level	Z=0.899, p=0.368	Z=2.500, p=0.012

Table 4.2 shows that HAH patients who died at home began their HAH care significantly closer to death than those who died as inpatients (8 versus 31 days). There was no significant difference in the hours of HAH input received. This mirrors the results of the observational study.

The univariate analysis shows there is a significant association between actual HAH input and home death. A further investigation of this relationship through logistic regression analysis is therefore warranted.

4.3.2 Comparing intervention group patients admitted and not admitted to HAH

In order to identify variables for entry into the logistic regression alongside HAH input, intervention patients admitted to HAH were compared to intervention patients not admitted. These groups will be referred to as "admitted HAH patients" and "non-admitted HAH patients" respectively. Variables which differ between groups at $p<0.2$ will be entered into the logistic regression analysis. Any variables which differed between the control and intervention groups at $p<0.2$ in the previous chapter will similarly be considered for entry into the regression analysis.

- HAH referral details

Table 4.3 shows that patients who were admitted to HAH had significantly longer median survival from referral (16 days) than non-admitted HAH patients (8 days). The groups did not differ in location at referral (home or inpatient).

Table 4.3: Referral details

	HAH not admitted (n=73)	**HAH admitted (n=113)**	**Significance level**
Location at referral:	**n (%)**	**n (%)**	
Home	48 (65.8)	79 (69.9)	X^2=0.188, d.f.=1,
Inpatient care	25 (34.2)	34 (30.1)	p=0.665
Survival after referral	**Median (i.q.r.)**	**Median (i.q.r.)**	
Days	8 (15.5)	16 (37.5)	Z=2.978, p=0.003

- Demographic and clinical variables

Tables 4.4 and 4.5 show demographic and clinical data for admitted and non-admitted HAH patients. Some categories were collapsed for social class and diagnosis in Table 4.5 to reduce the number of cells with expected frequency below five (Siegel and Castellan, 1991). More detailed tables for these two variables are presented in Appendix 4, Table 4.1 and 4.2.

Table 4.4: Informal support for non-admitted and admitted HAH patients

	HAH not admitted (n=73)	HAH admitted (n=113)	Significance level
Living alone:	**n (%)**	**n (%)**	
Yes	17 (24.3)	22 (19.6)	
No	53 (75.7)	90 (80.4)	X^2=0.310, d.f.=1, p=0.578
Next of kin:			
Husband	19 (26.0)	27 (23.9)	
Wife	27 (37.0)	43 (38.1)	
Son	2 (2.7)	13 (11.5)	
Daughter	15 (20.5)	18 (15.9)	
Other[1]	7 (9.6)	09 (8.0)	
None recorded	3 (4.1)	13 (2.7)	X^2=0.5280, d.f.=5, p=0.383

[1]Other: siblings, daughters in law, nieces, grandchildren, parents (n cases) and friends, a landlady and a lodger (n cases).

There were no significant demographic or clinical differences between admitted and non-admitted HAH patients ($p<0.05$). Survival from diagnosis differed at $p<0.1$ and will be considered for the logistic regression analysis (Table 4.5). This measure was only available for patients on the East Anglian Cancer Registry, not for the patient sample as a whole.

There were no differences between admitted and non-admitted HAH patients on any of the measured characteristics of the primary health care team (Table 4.6).

Table 4.5: Cause of death, survival, diagnosis, age, sex and socioeconomic status

	HAH not admitted n=73	HAH admitted n=113	Significance level
CAUSE(S) OF DEATH:	**n (%)**	**n (%)**	
Only cancer cause(s)	48 (65.8)	76 (67.3)	
Both cancer and non-cancer causes	14 (19.2)	20 (17.7)	
Only non-cancer cause(s)	11 (15.1)	17 (15.0)	X^2=0.068, d.f.=4, p=0.967
SURVIVAL FROM DIAGNOSIS: (Cancer Registry data)	**Median (i.q.r.) (n=61)**	**Median (i.q.r.) (n=93)**	
Days between diagnosis and death	187 (784.5)	392 (883.5)	Log Rank statistic=2.95, d.f.=1, p=0.0861
Diagnosed within a month of death			
	n (%)	**n (%)**	
Yes	4 (6.6)	5 (5.4)	
No	57 (93.4)	88 (94.6)	Fisher's Exact Test, p=0.741
DIAGNOSIS:			
Cancer			
Breast	4 (5.5)	10 (8.8)	
Gastrointestinal	16 (21.9)	27 (23.9)	
Genitourinary	9 (12.3)	23 (20.4)	
Lung	8 (11.0)	8 (7.1)	
Cancer other	26 (35.6)	28 (24.8)	
Non-cancer	10 (13.7)	17 (15.0)	X^2=5.030, d.f.=5, p=0.412
AGE:	***Mean (s.d.)***	***Mean (s.d.)***	
	70.9 (16.0)	71.9 (14.9)	t=0.440, d.f.=184, p=0.660
SEX:	**n (%)**	**n (%)**	
Females	32 (43.8)	60 (53.1)	
Males	41 (56.2)	53 (46.9)	X^2=1.174, d.f.=1, p=0.279
SOCIOECONOMIC AREA:	**Median (i.q.r.)**	**Median (i.q.r.)**	
Jarman UPA score.	-0.940 (22.863)	-0.943 (19.727)	Z=0.180, p=0.857
Townsend index.	-0.815 (4.385)	-0.550 (3.811)	Z=0.597, p=0.563
SOCIAL CLASS:	***n (%)***	***n (%)***	
I	12 (16.7)	10 (9.5)	
II	18 (25.0)	22 (21.0)	
IIIN	6 (8.3)	15 (14.3)	
IIIM	20 (27.8)	26 (24.8)	
IV and V	16 (22.2)	32 (30.5)	X^2=4.561, d.f.=4, p=0.335

Table 4.6: GP and district nurse characteristics

	HAH not admitted	HAH admitted	Significance levels
GP LIST SIZES	**Median (i.q.r.)** (n=65)	**Median (i.q.r.)** (n=105)	
GP total list size	1931 (604.5)	1818 (606)	Z=1.223, p=0.221
List size aged 65-74	123 (104)	143 (104)	Z=1.137, p=0.256
List size aged > 75	122 (102.5)	123 (93.5)	Z=0.587, p=0.557
Proportion of rural patients	0.252 (0.445)	0.175 (0.315)	Z=0.778, p=0.437
GP PRACTICE CHARACTERISTICS	**Median (i.q.r.)** (n=73)	**Median (i.q.r.)** (n=113)	
Number of partners:	5 (2)	5 (2)	Z=1.140, p=0.254
Training practice status:	**n (%)**	**n (%)**	
Yes	44 (61.1)	60 (53.6)	
No	28 (38.9)	52 (46.4)	X^2=0.730, d.f.=1, p=0.393
Fundholding practice:	**n (%)**	**n (%)**	
Yes	14 (19.4)	27 (24.1)	X^2=0.314, d.f.=1, p=0.575
No	58 (80.6)	85 (75.9)	
DISTRICT NURSE TEAM			
Team based at surgery:	**n (%)**	**n (%)**	
Yes	42 (60.0)	73 (65.8)	
No	28 (40.0)	38 (34.2)	X^2=0.392, d.f.=1, p=0.531
	Median (i.q.r.) (n=70)	**Median (i.q.r.)** (n=111)	
Team size:	4 (2)	4 (2)	Z=0.560, p=0.576
DN sisters and RGNs in team	2 (2)	2 (2)	Z=0.857, p=0.392

- *NHS service input*

There were no differences between patient groups in recorded contact with hospital or specialist oncology services during the course of illness (Table 4.7). These data related to patients registered on the EACR only, thus there were many missing values. It was not considered appropriate to assume that patients who were not found on the EACR had no specialist oncology input and code them accordingly. Apart from constituting a certain amount of guesswork, this would confound presence of specialist input with having a diagnosis of cancer versus non-cancer.

Table 4.7: Cancer Registry records of contact with hospital (non-admitted HAH n=61, admitted HAH n=93)

	HAH not admitted	HAH admitted	Significance level
In contact with hospital	**n (%)**	**n (%)**	
Yes	61 (100.0)	91 (97.8)	
No	0 (0.0)	2 (2.2)	Fisher exact test, p=0.518
In contact with an oncology department			
Yes	25 (61.0)	45 (48.4)	
No	36 (59.0)	48 (51.6)	X^2=0.543, d.f.=1, p=0.461

Table 4.8 shows the proportion of patients who were in contact with a service in their last year of life. Admitted HAH patients were significantly more likely to have had Marie Curie input than non-admitted HAH patients ($p<0.05$). Variables which differed at $p<0.2$ and were considered for further logistic regression analysis were hospice care, Flexible care, district nursing, night nursing and hospital day case care.

Table 4.8: Number (percentage) of patients who received a service in their last year of life

	HAH not admitted n=73	HAH admitted n=113	Significance level
Acute hospital inpatient	47 (64.4)	61 (54.0)	X^2=1.566, d.f.=1, p=0.211
Acute hospital daycase	19 (26.0)	18 (15.9)	X^2=2.240, d.f.=1, p=0.135
Acute hospital outpatient[1]	53 (72.6)	72 (63.7)	X^2=1.211, d.f.=1, p=0.271
Hospice inpatient	20 (27.4)	47 (41.6)	X^2=3.286, d.f.=1, p=0.070
Continuing care beds	5 (6.8)	6 (5.3)	Fisher's Exact Test, p=0.754
Cardio-thoracic specialist inpatient	6 (8.2)	5 (4.4)	Fisher's Exact Test, p=0.345
District nursing	61 (83.6)	104 (92.0)	X^2=2.390, d.f.=1, p=0.122
Night nursing	12 (16.4)	31 (27.4)	X^2=2.430, d.f.=1, p=0.119
Macmillan nursing	19 (26.0)	32 (28.3)	X^2=0.030, d.f.=1, p=0.862
Marie Curie	22 (30.1)	76 (67.3)	X^2=23.047, d.f.=1, p<0.001
Other community trust care	20 (27.4)	25 (22.1)	X^2=0.416, d.f.=1, p=0.519
Flexible care	8 (11.0)	26 (23.0)	X^2=3.542, d.f.=1, p=0.060

Table 4.9 shows that when patients received care, admitted HAH patients had a significantly greater amount of district nursing, Marie Curie and Flexible care nursing than non-admitted HAH patients ($p<0.05$). Hospice care differed at $p<0.2$ and was considered for logistic regression analysis.

Table 4.9: Amount of input per patient in the last year of life for those patients who had a service. Median (i.q.r.)

	HAH not admitted	n	HAH admitted	N	Significance level
Acute hospital inpatient days	23 (25)	47	17 (25)	61	Z=0.840, p=0.401
Acute hospital daycase appointment	2 (6)	19	1.5 (2)	18	Z=0.584, p=0.559
Acute hospital outpatient appt[1]	5 (7.5)	53	5 (7)	72	Z=0.221, p=0.825
Hospice inpatient days	11.5 (17.8)	20	18 (28)	47	Z=1.803, p=0.071
Continuing care bed days	30 (39.5)	5	33 (39)	6	Z=0.457, p=0.647
Cario-thoracic specialist inpatient days	12.5 (46)	6	11 (11.5)	5	Z=0.915, p=0.360
District nursing hours	16.8 (20.09)	61	25.2 (36.8)	104	Z=2.027, p=0.043
Night nursing hours	3.1 (6.6)	12	2.4 (4.08)	31	Z=0.650, p=0.516
Macmillan nursing hours	1.8 (3.2)	19	2.8 (3.1)	32	Z=0.605, p=0.545
Marie Curie nursing hours	15.5 (19.1)	22	45 (76.8)	76	Z=3.651, p=0.000
Other community trust hours	1.4 (1.2)	20	1.7 (2.6)	25	Z=0.709, p=0.478
Flexible care hours	5.1 (10.1)	8	16.3 (67.4)	26	Z=2.2, p=0.030

Table 4.10: Onset of care for those patients who received a service. Days before death. Median (i.q.r.)

	HAH not admitted	n	HAH admitted	n	Significance level
Acute hospital inpatient	132 (196)	47	188 (221)	61	Z=0.8149, p=0.415
Acute hospital daycase	205 (240)	19	223.5 (206)	18	Z=1.1700, p=0.242
Hospice inpatient	16.5 (75.5)	20	57 (114)	47	Z=2.4739, p=0.013
Continuing care beds	77 (329)	5	123.5 (177)	6	Z=0.000, p=1.000
Cardio-thoracic specialist inpatient	184 (279.5)	6	325 (214.5)	5	Z=1.189, p=0.234
District nursing	152 (241)	61	183 (276)	104	Z=0.373, p=0.709
Night nursing	8 (80)	12	12 (23)	31	Z=0.095, p=0.924
Macmillan nursing	62 (85)	19	107.5 (171)	32	Z=2.231, p=0.026
Marie Curie nursing	12 (25.3)	22	35.5 (80.5)	76	Z=2.602, p=0.009
Other community trust care	49 (84.3)	20	110 (132)	25	Z=2.319, p=0.020
Flexible care	12.5 (81.8)	8	55 (117.8)	26	Z=1.686, p=0.092

Table 4.10 shows that when patients received care, admitted HAH patients had a significantly earlier onset of hospice care, Macmillan nursing, Marie Curie nursing and other community trust primary care compared to non-admitted HAH patients ($p<0.05$). Flexible care onset differed at $p<0.2$ and was considered for logistic regression entry.

4.3.3 Summary of variables for entry into logistic regression

This section summarises the variables which should be considered when attempting to control for case mix in the logistic regression analysis. Table 4.11a and b and summarise variables which differed between admitted and non-admitted HAH patients at $p<0.2$. In addition Table 4.11a and c show variables which differed between the control and intervention groups at $p<0.2$ in the previous chapter. Although there were no significant differences between the control and intervention arm of the RCT, there were still variables which differed at $p<0.2$, and which should be included in the logistic regression analysis if using a lax entry criterion as recommended by Altman (1990).

Table 4.11a: Variables showing a difference between groups at p<0.2

	Control patients versus patients allocated to HAH	Patients allocated to HAH: admitted versus not admitted
Survival after referral		p<0.05
Survival after diagnosis		p<0.1
Diagnosis	p<0.2	
GP total list size	p<0.2	
Training practice	p<0.2	
Fundholding practice	p<0.2	

Table 4.11b: Service input variables showing a difference between control group and patients allocated to HAH at p<0.2

	Input/ no input	Amount of input	Onset of care	n receiving care
Acute hospital daycase				48
Hospice inpatient				79
Cardio-thoracic specialist inpatient			p<0.1	16
District nursing				201
Night nursing		p<0.2		52
Macmillan nursing	p<0.2			68
Marie Curie nursing		p<0.2		119
Other community trust care			p<0.2	54
Flexible Care				45
Oncology contact	p<0.2	N/A	N/A	92

Table 4.11c: Service input variables showing a difference between admitted and non-admitted HAH patients at p<0.2

	Input/ no input	Amount of input	Onset of care	n receiving care
Acute hospital daycase	p<0.2			37
Hospice inpatient	p<0.1	p<0.1	p<0.05	67
Cardio-thoracic specialist inpatient				11
District nursing	p<0.2	p<0.05		165
Night nursing	p<0.2			43
Macmillan nursing			p<0.05	51
Marie Curie nursing	p<0.05	p<0.05	p<0.05	98
Other community trust care			p<0.05	45
Flexible Care	p<0.1	p<0.05	p<0.01	34
Oncology contact		N/A	N/A	70

4.3.4 *Treatment of variables for entry into analysis*

Survival after referral, survival after diagnosis and GP list size were subdivided on the basis of quartiles, in accord with Hosmer and Lemeshow's (1989) recommendations. Appendix 4, Table 4.3 shows the quartile values and the number of patients in each category.

Table 4.11b and c suggest that patient groups differed both in terms of amount and onset of service input. These dimensions were again found to be significantly, positively correlated, even when considering only patients who received care, i.e. when excluding zero values from analysis (Table 4.12).

Table 4.12: *Correlation between amount and onset of care. Patients receiving input only.*

	Spearman rank order correlation coeffient	Significance level
Acute hospital daycase (n=48)	0.3315	p=0.021
Hospice inpatient (n=79)	0.7189	p=0.000
Continuing care beds (n=12)	0.4351	p=0.157
District nursing (n=201)	0.4210	p<0.001
Night nursing (n=52)	0.3944	p=0.004
Macmillan (n=68)	0.5357	p<0.001
Marie Curie (n=119)	0.6381	p<0.001

Similarly to the observational study analysis we tried to avoid entering variables which correlated with each other, into the same logistic regression analysis. Thus amount and onset of care were analysed in separate analyses. Only for district nursing were patient numbers sufficiently to sustain a two by two subdivision of amount and onset. Appendix 4, Tables 4.4-4.6 show the analysis categories and their associated patient numbers.

4.3.5 Logistic regression: demographic and clinical variables

Variables considered were survival after referral, survival following diagnosis, diagnosis, GP list size, and GP practice training status and fundholding status.

There were missing values for GP list size and GP practice variables, hence their inclusion reduced the number of patients which could be included into the logistic regression analysis. Initial analysis showed that these variables were not significantly related to place of death (score statistic in the initial model were GP list size: 2.958, d.f.=3, p=0.398; fundholding status: 2.085, d.f.=1, p=0.149; training practice status: 0.010, d.f.=1, p=0.922). These variables were omitted from further analysis to enable the total patient sample to be used.

There were also missing values for survival following diagnosis as this variable only pertained to patients registered on the East Anglian Cancer Registry. Multiple logistic regression analysis showed that survival from diagnosis was not significantly associated with home death (score statistic = 6.525, d.f.=3, p=0.089). However, this was considered close enough to significance at $p<0.05$ to merit further investigation. Each of the analyses in section 4.3.6 and 4.3.7 were run with survival included. However, in no case did it show a significant relationship with home death. Only analyses without this variable are therefore reported, enabling inclusion of the total patient sample.

Table 4.13 shows the logistic regression model resulting from entering the remaining variables, diagnosis and survival from referral, into the analysis. Only survival from referral was significantly associated with

home death. The regression coefficients presented in the following tables are based on simple contrasts. However, repeated contrasts were also used to assess whether the regression coefficients of variable categories differed significantly from each other (Norusis, 1994).

Table 4.13: Association between clinical variables and home death. Simple contrasts. Variable coefficients which differ significantly at p<0.05 share the same superscript.

	Coefficient	SE	p	Odds Ratio (95% CI)
Survival from referral to HAH				
<= 4 days	1.678[A]	0.424	0.0001	5.353 (2.330, 12.299)
>4 and <=11 days	0.495[A]	0.388	0.2018	1.640 (0.767, 3.506)
>11 and <=32 days	0.853	0.390	0.0289	2.346 (1.092, 5.040)
>32 days	0			1
Constant	0.651	0.146	<0.0001	

n=229, 66.38% cases correctly classified; Model X^2=18.270, d.f. =3, p=0.0004; Number of outliers with SRESID of 2 or more =0; Residual X^2 for variables not in the equation =9.720 with, d.f .=5, p=0.0836; Goodness of Fit=228.995.

Referral to HAH within four days of death and between 11 and 32 days of death were both associated with increased likelihood of death at home. However, referral between four and 11 days before death did not significantly increase the probability of home death compared to early referral (>32 days before death).

This model only explained 1.3% more than a model based on the constant only (65.1%). It predicted 81.9% of home deaths and 37.5% of inpatient deaths correctly.

4.3.6 Logistic regression: demographic, clinical and service variables

Diagnosis, survival after referral, oncology specialist service contact, acute hospital day case appointments, hospice care, cardio-thoracic specialist inpatient care, district nursing, night nursing, Macmillan nursing, Marie Curie nursing and "other" community trust primary care were entered into the logistic regression analysis.

A first analysis was performed with service input variables categorised on the basis of onset of care. This is reported in detail below. A second logistic regression analysis was performed with service input categorised on the basis of amount of care and is reported in detail Appendix 4, Table 4.7. The second

analysis is only summarised in the text below. In the following descriptions of results no assumptions are made about cause and effect between predictor variables and outcome.

- Service variables subdivided on the basis of onset of care

Contact with oncology specialist services pertained only to patients who were registered on the East Anglian Cancer Registry and thus contained many missing values. Initial multiple logistic regression analysis showed that oncology input did not make a significant contribution to the model (final score statistic: 1.603, d.f.=1, p=0.206). Subsequent models are presented with oncology input excluded, enabling the total patient sample to be included in the analysis. Table 4.14 shows the model with the remaining variables included in the analysis.

Table 4.14: Demographic, clinical and service input variable analysis of likelihood of home death. Service variables subdivided on onset of care. Variable coefficients which differ significantly at p<0.05 share the same superscript.

	Coefficient	SE	p	Odds Ratio (95% CI)
Survival from referral to HAH			0.0001	
<= 4 days	2.530[A]	0.583	<0.0001	12.555 (4.004, 39.361)
>4 and <=11 days	1.044[A]	0.549	0.0569	2.841 (0.970, 8.325)
>11 and <=32 days	1.693	0.547	0.0020	5.435 (1.862, 15.870)
>32 days	0			1
Hospice inpatient care			<0.0001	
Input, late onset	-2.204[A]	0.490	<0.0001	0.110 (0.042, 0.289)
Input, early onset	-1.000[A]	0.522	0.0555	0.368 (0.132, 1.024)
No input	0			1
Night nursing care			0.0034	
Input, late onset	2.823	1.089	0.0096	16.824 (1.989, 142.314)
Input, early onset	1.600	0.705	0.0232	4.950 (1.244, 19.705)
No input	0			1
Marie Curie care			<0.0001	
Input, late onset	1.485	0.453	0.0011	4.414 (1.816, 10.730)
Input, early onset	2.458	0.556	<0.0001	11.679 (3.925, 34.755)
No input	0			1
Constant	1.727	0.449	0.0001	

n=229,77.29% cases correctly classified; Model X^2=90.490, d.f. =9, p=0.0000; Number of outliers with SRESID of 2 or more =6; Residual X^2 for variables not in the equation =17.644 with, d.f.=16, p=0.3451; Goodness of Fit=205.556.

As in the previous model, referral to HAH very close to death and between eleven and thirty two days of death was associated with a significantly increased likelihood of death at home. Referral between four and eleven days before death did not reach significance.

A late (<=45 days before death) onset of hospice care was associated with a significantly reduced likelihood of death at home, while an early hospice onset did not reach significance. Both night nursing and Marie Curie nursing were associated with increased likelihood of death at home, whether care began early or late. There was no significant difference between early and late onset for these services.

This model classified 88.6% of home deaths and 56.3% of inpatient deaths correctly. It classified more cases correctly overall compared to the previous model (77.3% versus 66.4%). There was some improvement in goodness of fit from 229.00 in the previous model to 205.56 in the current model.

- Service variables subdivided on the basis of amount of care

The full model is presented in Appendix 4, Table 4.7. Survival from referral displayed the same pattern as that in Table 4.14 above. The final model included the same services as that based on onset of care, but with Macmillan nursing added. For Marie Curie nursing both a high amount (>36 hours) and a low amount of care were associated with increased likelihood of home death, but a high amount significantly more so than a low amount. Hospice care was negatively associated with home death and night nursing positively associated, but in neither case was there a significant difference between high and low amount of input. While Macmillan nursing care was overall significantly associated with home death, neither the positive coefficient for a high amount (>2 hours) nor the negative coefficient for low amount differed significantly from no input.

There was little difference between the models based on onset and amount of care in terms of correct classification of cases (77.9% versus 79.5% respectively) and goodness of fit (205.56 versus 212.3 respectively).

4.3.7 Logistic regression: demographic, clinical, service variables and HAH input

Univariate analysis showed that onset of HAH care, but not amount, differed significantly between those who died at home and those who did not (Table 4.2). However, the Spearman rank order correlation coefficient between amount and onset of HAH care is 0.750 ($p<0.001$, $n=113$, patients receiving input only). Therefore, we again need to consider that any differences found in onset of HAH care may in part be a reflection of amount. There was no evidence that being allocated to HAH, but not admitted, increased the likelihood of death at home (section 4.3.1). Thus this is not included as a separate subcategory for the HAH service variable in the analysis below.

A first analysis was again performed with service input variables categorised on the basis of onset of care, reported in detail below. A second logistic regression analysis was performed with service input categorised on the basis of amount of care (Appendix 4, Table 4.8). The second analysis is only summarised in the text below.

- HAH and other service variables subdivided on the basis of onset of care

Apart from the addition of HAH, the variables entered into the logistic regression analysis were the same as those entered into the analysis in section 4.3.6. Table 4.15 reports the resulting model.

Late HAH onset of HAH care (<=12 days before death) was associated with an increased likelihood of home death, while an early onset was not significantly different from no input. Compared to the other variables in the current model, the association between HAH and home death is less than that of survival from referral, hospice care or Marie Curie care, as judged by regression coefficients and overall significance level. Its association may also be weaker than that of night nursing, but the latter variable has a large standard error.

Table 4.15: HAH, clinical and service input variable analysis of likelihood of home death. Service variables subdivided on onset of care. Variables for which coefficients differ significantly at p<0.05 share the same superscript.

	Coefficient	SE	p	Odds Ratio (95% CI)
Hospital at home care			0.0074	
Input, late onset	1.671	0.539	0.0020	5.316 (1.847, 15.303)
Input, early onset	0.574	0.529	0.2782	1.775 (0.629, 5.010)
No input	0			1
Survival from referral to HAH			0.0005	
<= 4 days	2.366[A]	0.636	0.0002	10.652 (3.066, 37.013)
>4 and <=11 days	0.902[A]	0.613	0.1410	2.463 (0.742, 8.182)
>11 and <=32 days	1.736	0.568	0.0023	5.674 (1.863, 17.284)
>32 days	0			1
Hospice inpatient care			0.0001	
Input, late onset	-2.232	0.517	<0.0001	0.107 (0.039, 0.296)
Input, early onset	-1.071	0.542	0.0480	0.343 (0.119, 0.991)
No input				
Night nursing care			0.0101	
Input, late onset	2.464	1.081	0.0226	11.752 (1.412, 97.791)
Input, early onset	1.520	0.729	0.0370	4.572 (1.096, 19.069)
No input	0			1
Marie Curie care			0.0006	
Input, late onset	1.144	0.481	0.0174	3.139 (1.223, 8.055)
Input, early onset	2.222	0.606	0.0002	9.229 (2.816, 30.239)
No input	0			1
Constant	1.786	0.459	0.0001	

n=229,79.91% cases correctly classified; Model X^2=101.757, d.f. =11, p=0.0000; Number of outliers with SRESID of 2 or more =8; Residual X^2 for variables not in the equation =18.251 with, d.f .=16, p=0.3094; Goodness of Fit=230.528.

The introduction of HAH into the analysis had no notable effect on the relationship between the other variables and place of death. As before hospice care was associated with reduced likelihood of home death, and night nursing and Marie Curie nursing with an increased likelihood. Late onset for these services was not significantly different from early onset. Survival from referral showed the same relationship with death at home as in previous models.

Inclusion of HAH input into the analysis did not really improve our ability to classify place of death correctly. The model including HAH classified 79.9% of cases correctly (90.6% of home deaths, 60.0% of inpatient deaths) compared to 77.3% in the previous model. Its goodness of fit was somewhat worse (230.53) than in the previous model (205.56).

- HAH and other service variables subdivided on the basis of amount of care

The full model is presented in Appendix 4, Table 4.8. A high amount of HAH care (>51 hours) was associated with an increased likelihood of home death, while a low amount was not significantly different from no input.

The association between HAH and home death was weaker than that of survival from referral, hospice care, night nursing or Marie Curie care, as judged by the regression coefficients and their overall significance level. The introduction of HAH in the model changed the coefficients of the other variables very little. As before hospice care was negatively, and night and Marie Curie nursing positively, associated with home death. Only for Marie Curie nursing was there a significant difference between high and low input. While Macmillan nursing overall showed a (near) significant association with home death (p=0.0501), neither a high amount nor a low amount of input on their own showed a significant association with death at home.

There was virtually no difference between the models based on onset and amount of care in terms of correct classification of cases (79.9% and 80.8% respectively). The goodness of fit may have been somewhat better for the model based on amount of care compared to onset (201.8 versus 230.5).

4.4 CHAPTER 4 SUMMARY AND DISCUSSION

The discussion first considers the evidence that HAH was associated with an increase in home death. Second, it considers the extent to which other home care support may be associated with home death.

In the observational study we chose to emphasise the logistic regression model in which service variables were categorised on the basis of onset rather than on amount, because the former appeared more informative in illustrating what was happening. Otherwise the models appeared of equal value as judged by their percentage of cases classified correctly and goodness of fit. In the present study we will discuss results

both from the logistic regression model with services categorised in terms of onset and the model with services categorised in terms of amount, as it was less clear which model was the more informative.

4.4.1 The evidence for an impact of HAH care on home death

Key points to note from the current logistic regression analyses include that HAH showed an association with home death. However, its role was no greater, possibly less, than that of other services, and knowledge of HAH input did not improve our ability to predict place of death. The timing of the HAH referral was more important than the HAH input itself.

A late onset of HAH care (<=12 days before death) was significantly associated with an increased likelihood of death at home, while an early onset was not. A high total amount of HAH care (>51 hours) was also significantly associated with home death, but not a low amount. Although the positive correlation between onset and amount of HAH care suggests that an early onset of HAH care should be associated with a high total amount of care and a late onset with a low amount, results may suggest that home death is most likely to occur when there is a combination of a late onset of HAH care with a high total amount of input. That is, when there is a brief period of intensive input close to death.

Where a significant association between HAH and home death was found, the relationship between HAH and home death may have been a function of the patient's own ability to remain at home. A late HAH onset by definition means that the patient was at home at some point during his or her last 12 days of life. Likewise, patients who spent more time at home, perhaps particularly during the terminal period when high levels of care may be needed, would have had greater opportunity to accumulate HAH hours.

The relationship between HAH and home death was considerably weaker in the logistic regression analysis for the RCT sample than in the analysis for the observational study. In the observational study the odds ratio was 494.2 (CI 25.0-9756.1) for late onset of HAH care and 7.2 (CI 1.6-32.3) for early onset. Odds ratios for the RCT sample were 5.3 (CI 1.8-15.3) for late onset and not significant for early onset of care.

Furthermore HAH was the strongest predictor of home death in the observational study, while in the RCT analysis it appears no more important than other variables.

This lends support to our hypothesis that case mix differences for a large part could account for the association between HAH and home death in the observational study. As the RCT study sample consisted only of patients referred to HAH, it should be considerably more homogenous than that of the observational study. Case mix differences between those who received HAH and those who did not should therefore be greatly reduced between the first and the second study. Once case mix differences were reduced, the association between HAH and home death also appeared to be considerably reduced. Thus the strong association between HAH and home death in the observational study may largely have been due to case mix. We should note that among the patients referred to HAH, there was a smaller difference in percentage of home deaths between recipients and non-recipients of HAH care among RCT patients (78% and 53% respectively) than among observational study patients (86% and 44% respectively). Thus any potential impact of HAH on home death may have changed over time. However, these differences were not large and may result from random variation.

It is not clear from the present data that HAH had an impact on place of death. The randomised controlled trial did not show a significant difference between control patients and patients allocated to HAH. However, it has to be recognised that the study was underpowered. While there was a strong association between HAH and home death in the observational study, this association was considerably smaller when a similar analysis was performed with a more homogenous patient group (i.e. RCT sample), thus leading us to suspect that the strong association in the first study largely could be attributed to case mix differences. While a positive association does remain between actual HAH input and home death in the final logistic regression analysis, it is difficult to disentangle the effect of HAH from that of the patient's own ability to remain at home, i.e. from the characteristics of the patient and his/her context. Even if the positive association does reflect an effect of HAH on place of death, this relationship is no greater than that observed between other palliative care services, such as Marie Curie nursing or hospice care, and home death. It has to be recognised that while the RCT sample was more homogenous than the observational

study sample, thus reducing case mix differences, it probably represented patients who were in a better position to die at home than most, both through their characteristics and their other service input. Additional home care may have less impact within such a patient group than within a group which commands a lower level of resources.

4.4.2 The association between other home care services and home death

In the present logistic regression analysis Marie Curie and night nursing services appeared to show a stronger positive association with home death than HAH. Their association with home death was largely independent of HAH input, as the regression coefficients for these services changed very little when HAH was introduced into the multivariate analysis. Although patients admitted to HAH were more likely to have had Marie Curie nursing, and more of it, than those not admitted, the services' association with home death appear independent of each other.

The overall association between Marie Curie nursing, night nursing and home death was not reduced from the observational study to the present study. Thus although the patient sample had become more homogenous, the positive relationship between these services and home death did not change. This may mean that the observed associations for Marie Cure and night nursing are less attributable to differences in case mix than was the case for HAH. However, it was specifically the case mix differences between patients who did and did not receive HAH which were reduced between the two studies. We cannot assume that they were similarly reduced between patients who did and did not receive Marie Curie or night nursing, although the greater homogeneity of the RCT sample would make this likely.

In the present analysis the start date of Marie Curie and night nursing was not important, as long as input was received. There was no significant difference between early or late onset of care in their association with home death. However, the amount of care appeared to matter. Patients who received a high amount of Marie Curie care (>36 hours) were significantly more likely to die at home than those who received a low amount, although both a high and low amount were significantly associated with home death. For night

nursing it was only a high amount of nursing care (>3 hours) which was significantly associated with death at home, while a low amount was not.

As the timing of onset of care appeared unimportant in the present analysis, it is more difficult to argue that the association between Marie Curie, night nursing and home death simply shows that the patients able to remain at home closest to death were more likely to receive these services towards the end of life. Nevertheless, the possibility remains that patients who were best able to remain at home received the highest amount of home care. The positive association between these home services and home death may still to some extent be due to patient characteristics.

We should note that district nursing no longer was significantly associated with home death in the present study. However, as nearly all patients (>80%) now had district nursing, which is close to a situation in which district nursing is held constant, we may be less likely to see an effect of this variable.

A late onset of hospice care (<=45 days) was associated with a significantly reduced likelihood of death at home compared to no input, while an early onset made no difference. The observed association may therefore be a function of place of death.

In summary the results suggest that professional home support does play a role in home death, but that HAH is not necessarily the most important of these. For Marie Curie and night nursing there may be less suggestion that the results can be attributed to case mix differences overall or to services being received by patients who were able to remain at home close to death. Nevertheless our analysis does not allow us to fully discard these explanations.

4.4.3 Non-service variables and home death

Length of survival following referral to HAH was the only variable associated with home death alongside service input variables. HAH referral was not associated with likelihood of receiving HAH in the present

study, as all patients had been referred. This variable may be interpreted as an indicator of when HAH was perceived to be required. This would be the point when relatively intensive care input would be needed, and in most cases when death was believed to be imminent. If this interpretation is correct, our data may again suggest that patients who already at an early stage require a high level of care are less likely to remain at home and die there. Those referred approximately one month or less from death were more likely to die at home than those referred earlier.

Survival from referral of less than four days, and survival of between 11 and 32 days, were significantly positively associated with home death, while survival from referral of between four and 11 days was not. This fluctuation may be due to chance. However, another possible interpretation can be put forward, assuming there is a delay between attempts at mobilising support and its actual introduction. If patients are perceived to reach a high level of care need within four days of death, existing home resources may be able to cope, even if this consists mainly of informal support with limited professional backup. Introduction of HAH or any other comprehensive package of care may be difficult to achieve at such short notice, but fairly intensive care may be provided with limited resources for a very short period. However, beyond four days, existing home resources may become over-stretched, while it may still be short notice to get a full care package in place to relieve informal carers. If the patient is perceived to require a high level of care more than eleven days before death, there may time to get a care package in place and give proper support to informal carers. However, even with added support there may be a limit to how long a patient can remain at home. Provision of high intensity input at home beyond one month may be pushing this limit.

This interpretation is based on the large, but not unreasonable, assumption that additional home care may prolong the period for which patients can be sustained at home. It is also probably too simplistic in its view of the interplay between variables and is based on somewhat artificial categorisation of the survival variable. However, it does consider that it may not be home care per se, and not the timing or amount of care per se, but the relationship between professional home care, course of illness and existing informal care resources which may affect home death. We may need to obtain a more in-depth view of the patient's situation and the course of events to understand how home care may help more patients to die at home, if

they so wish.

4.4.4 Investigation into the reasons for inpatient admissions

The results suggest that professional home support, such as Marie Curie and night nursing, probably is of importance in enabling patients to die at home, although one cannot be certain to what extent case mix differences play a part in the associations observed. However, on the basis of the RCT and the subsequent logistic regression analysis, it appears questionable whether additional high intensity home care such as HAH can make any substantial contribution if introduced on top of good existing home care provision, and among patients who are in a good position to die at home. The observational study suggested that patients referred to HAH probably were those already most likely to die at home, either because of their demographic or clinical characteristics, or because they had more home care services than those not referred. The fact that they were referred to HAH furthermore means they were identified as suitable to die at home by a health professional. The high proportion of home deaths (53%, Table 4.1) among RCT patients who did not receive HAH, appears to confirm the privileged position of patients referred to HAH in relation to this outcome variable. In addition, patients who did receive HAH care were those who also had the most other home care (Tables 4.8-9).

The current research does not enable us to assess what the impact of a HAH service would be on patients more disadvantaged in relation to home death, e.g. the old, those of low socioeconomic status, patients with little or no access to other home care provision. However, it does raise the question whether additional home care can contribute anything at the other end of the spectrum, that is, among patients who appear to be advantaged in relation to home death. This can be investigated further within the current research.

It may be that the high percentage of home deaths in the RCT group represents a level beyond which the home death rate cannot realistically be increased. It would be naïve to think that professional home care could solve all the problems facing patients and their families, or that it would at all times be appropriate. Patients within the RCT group who died in inpatient care may represent the cases for whom additional

home care would not have helped, and for whom place of death was determined by factors unrelated to level of home care provision. For instance, our data suggest that it may be difficult to meet high care needs at home over a prolonged period. This may be due to insufficient home support, but may also mean there is a limit to how long one can turn a home into a hospital and have a continuous presence of health professionals, before the situation becomes untenable. In the latter case added home support does not provide the solution.

An investigation into the problems associated with final inpatient admissions for RCT patients, and any relevance of added home care in this context, requires a switch from group statistics to a consideration of individual cases. Content analysis will be conducted to investigate the reasons for RCT patients' final inpatient admission according to their GPs, district nurses and informal carers. For each patient we will consider whether insufficient home care was perceived to be directly implicated in the inpatient death, may have ameliorated the factors precipitating such a death, or was of little or no relevance to the place of death. In this analysis it is not possible to assess whether home care would actually have changed the place of death. We can, however, tell whether respondents felt that home care had something further to contribute in the individual case, or whether the perceived reasons for inpatient admission perhaps were beyond the scope of the types of home support available in the area.

CHAPTER 5: CONTENT ANALYSIS OF REASONS FOR INPATIENT DEATHS

5.1 INTRODUCTION

In the previous chapter we asked whether the RCT sample may represent patients for whom additional home care had little impact because their likelihood of home death already was high, due to their characteristics and/or existing level of home care. As such, RCT patients who died in inpatient care may represent those cases who would die as inpatients regardless of level of home support, because their problems were such, or their preference for place of death was such, that additional home care would have made little difference. Put differently, the RCT patients may represent the limits to the number of home deaths which could be achieved through the type of home care services available locally. There may be problems which are not amenable to support at home at all or which require other, possibly specialist, types of support. On the other hand, if there is indication that there was insufficient home nursing for RCT patients who died in inpatient care, additional home care may still be able to make a considerable contribution even among patients who appear at an advantage in relation to home death. We need to consider whether any lack of support may be due to the trial (control condition) or otherwise may illustrate problems in introducing home care, rather than level of care provision within the area *per se*.

This chapter presents a content analysis (Holsti, 1969) of open ended, retrospective survey responses relating to the inpatient deaths of individual RCT patients, in order to investigate whether insufficient professional home support was perceived to be a contributing factor in precipitating inpatient death, or whether other factors appeared more important. We are obtaining the assessment of people who knew each patient and his/her situation by asking the patient's informal carer, district nurse and GP to explain the reasons behind the inpatient death. We are moving beyond aggregate measures of association towards an inside account of the individual situation. This enables us to consider whether deficiencies in home support featured in any given case, whether problems and choices which precipitated end stage inpatient admissions were amenable to additional home care, or whether level of home care appeared irrelevant. There may be many situations in which home death is not possible or appropriate, regardless of level of professional

home support available. The current analysis will help illuminate this issue in a way that the analysis in previous chapters could not. However, we can only assess whether respondents' accounts suggest that patients' situation could be improved by added home care. We cannot determine whether it actually would have made any difference to place of death. The analysis will furthermore identify potential issues for further research and future interventions to increase home deaths.

Our approach is similar to that of past studies investigating reasons for inpatient deaths retrospectively (Doyle, 1980, Wilkes, 1984, Dunlop et al, 1989, Herd, 1990, Lubin, 1992, cf. Chapter 1, Section 1.2). However, in most of these studies the assessment was made by hospital staff or derived from patient notes. Only Wilkes (1984) obtained the assessment of bereaved relatives, and it is unclear whether the relatives themselves volunteered the reasons or responded to researcher generated categories. In the case of Doyle (1980) it is not possible to ascertain who made the assessments or how the categories were derived. The strength of the present study is that we asked the people who knew the patient and his/her home situation both from a personal (informal carer) and professional (GP and district nurse) perspective. These should be the people in the best position to assess the reasons behind end stage inpatient admissions. We are furthermore obtaining the views of more than one respondent for each patient, and allowing respondents to provide their own explanations rather than using predetermined categories.

As the categories for the content analysis were not predetermined, the analysis developed as an evolving process, and the outcome of the first step of analysis was used to feed into the next stages of analysis (Ritche and Spencer, 1994). It is therefore not appropriate to attempt a rigid division between "analysis" and "results" in the layout of this chapter. Instead we provide details of the process and format of data collection and the resulting response rates first. Next an outline of the analysis is provided, so that the reader can gain an overview of the rest of the chapter. In the main body of the chapter details of the analytic process are reported alongside the results.

5.2 DATA COLLECTION

5.2.1 Process and format

As part of the randomised controlled trial of HAH, questionnaires were mailed to the patient's GP, district nurse and family carer within six weeks of the patient's death. One reminder was mailed to non-respondents. The questionnaire assessed the quality of HAH care versus standard care (primary and secondary) during the last two weeks of life, to serve the broader evaluation of the HAH service (Grande et al, 1998, 2000). However, the questionnaire also included an open ended question which directly addressed factors associated with place of death, which is the subject of the present chapter.

Respondents were asked the following open ended question if the patient died in inpatient care: *What was/ were the main reason(s) that he/she was admitted to hospital/ hospice?* The same question was not asked for patients who died at home. This was based on the assumption that it is more difficult to identify reasons for a non-event (i.e. inpatient admission did not take place) than it is to pinpoint the immediate causes of an event (final inpatient admission). In particular this would be the case for family carers who would not have been exposed to a range of similar situations on which they could base comparisons. Put differently, it is easier to identify reasons why something went wrong (why I had an accident when travelling to work today), rather than what went right (why my journey to work today occurred without incident). We should, however, note that it is the cognitive exercise of "identifying reasons" which is easier when explaining an event. While it is easy to identify difficulty in pain control as a reason for inpatient admission, it is less obvious to identify absence of pain control problems as a reason for home death. Yet the underlying issue of pain control may be equally important in both cases.

5.2.2 Response rates

Of the 229 patients who entered the RCT, a key carer could be identified in 198 (86%) cases (91% for controls and 85% for the intervention group). A GP and district nurse could be identified for 228 (99.6%)

cases. Questionnaire response rates were 144 (73%) of 198 for carers, 194 (85%) of 228 for GPs, and 225 (99%) of 228 for district nurses.

There were 80 inpatient deaths. For these there were 78 district nurse responses, 58 GP responses and 50 carer responses. Most cases therefore had their inpatient admission explained by more than one respondent. Table 5.1 shows the combination of responses for each patient.

Table 5.1: Responses available per patient

District nurse, GP and carer response:	38 patients
District nurse and GP response:	19 patients
District nurse and carer response:	12 patients
District nurse only:	9 patients
GP only:	1 patient
No response:	1 patient

Three of the 80 inpatient deaths could not be analysed due to a lack of information (Case no. 283, 385, 403). For two of these patients there was only a district nurse response to say that the patient was unknown to them. For one case there was no reply from the district nurse, GP or informal carer.

5.3 OUTLINE OF CONTENT ANALYSIS

This content analysis explored the perceived reasons for end stage inpatient admissions as reported by GPs, district nurses and informal carers. The focus of the analysis was the role played by deficiencies in professional home support, whether in the form of improved HAH care or other support. Whenever the researcher was aware that the research question influenced how the data were interpreted, this was noted (Brody, 1992, Mason, 1996).

5.3.1 Analysis framework

While analysis categories, as noted, were not determined from the outset, the focus of the research question influenced the ways in which the data could be viewed. Furthermore, categories were necessarily influenced by findings from past research investigating reasons for inpatient deaths (Doyle, 1980, Wilkes, 1984, Dunlop et al, 1989, Herd, 1990, Lubin, 1992). Nevertheless, there was some scope for letting categories emerge from the data, in a manner similar to a grounded theory approaches represented in qualitative research (Glaser and Strauss, 1967, Strauss and Corbin, 1990, Pope et al, 2000).

In order to provide a systematic approach to the analysis, the framework approach, as described by Ritchie and Spencer, (1994) was adopted for the current study. Whilst developed as form of qualitative analysis, it is aimed at situations in which the objectives of the investigation are set in advance; "The data collection tends to be more structured than would be the norm for much other qualitative research and the analytical process tends to be more explicit and more informed by a priori reasoning" (Pope et al, 2000). It was therefore considered suitable for the content analysis in the present chapter.

5.3.2 Outline of chapter analysis

From the outset we considered our analysis to have a single theme, labelled "scenarios precipitating inpatient death". Whilst content analyses may yield several "themes", the nature of the data set and the focus of the research suggested our analysis was best structured by using the one, overarching theme ("scenarios") and identifying the range of components and configurations within it.

Using Ritchie and Spencer (1994) as a guide, the first step of analysis involved familiarisation with the range of reasons for inpatient deaths, regarded as the components of our "scenarios". Next the reasons were grouped into descriptive categories and the text indexed according to these categories. This constituted a simple content analysis, whereby similar themes and concepts are grouped through scrutiny of text segments (Holsti, 1969). The aim was to gain an understanding of the range of explanations rather than to

produce frequency counts. The categories derived and an overview of the data set are provided within the relevant sections of the chapter.

Rather than considering categories of explanations as independent of each other, the analysis next considered how they fit together within a framework of "scenarios". Different respondents assessed the same patient and emphasised different aspects in their reasons for inpatient admissions. These explanations can be regarded as complementary rather than conflicting accounts of the same situation. Thus there was a need to find a way of representing the situation as a whole to encompass the different types of explanation. A model was therefore next created to illustrate how the range of explanations for inpatient deaths within the data set were likely to relate to each other. For instance, level of care need and insufficient home support may both be reported as reasons for a patient's inpatient admission. Level of care need will influence how much home support is required. Whether home support is deemed insufficient will depend on care need. These reasons represent complementary sides to the same situation. The model suggested that certain explanations should tend to occur together while others should not.

In the subsequent analysis all responses relating to the same patient were considered together as one case. Using the category labels created earlier, an abstracted summary was created for each case, and cases were grouped according to the types of explanations they represented. A key division was made between cases for which insufficient home support was and was not mentioned, in line with the focus of our research: to assess whether patients could have benefited from added home care or not. Using the terminology of Ritchie and Spencer (1994) this abstracting and grouping represent the process of charting the data.

We considered whether the explanations provided for each case formed consistent scenarios with reference to the developed model. In particular we investigated whether cases for whom inpatient death was attributed to insufficient home care, formed different configurations to cases in which lack of home care was not mentioned. If configurations were qualitatively different and there was internal coherence within case accounts, it was felt that we could be more confident about the validity of the explanations and our ability to identify situations for which added home care would have helped. The construction of the model

and its application to the data would correspond with Ritchie and Spencer's (1994) stage of mapping and interpretation. When there was mention of insufficient home support, we considered the types of home care implicated and the problems associated with their provision.

The cases were reviewed and discussed with an oncology nurse experienced in palliative care in the community. Each step of analysis is outlined in detail below. When cases are assessed, case descriptions and quotes are used extensively to enable the reader to assess the validity of the conclusions independently (Seale and Silverman, 1997).

5.4 ANALYSIS AND RESULTS

5.4.1 Familiarisation with the data

Following Ritchie and Spencer (1994), as a first step the material was read through and key ideas and recurrent themes listed. All explanations of why end stage inpatient admissions occurred were scrutinised in full. The researcher read through the printouts relating to such inpatient deaths several times and wrote notes in the margins for each case as to what type of explanation it was. It was unavoidable that categories derived from past research were held in mind during this exercise (Doyle, 1980, Wilkes, 1984, Dunlop et al, 1989, Herd, 1990, Lubin, 1992). The note taking, however, aimed to break through, refine and add to these categories.

After note taking the researcher listed all the reasons for inpatient admissions on a word processor, so that similar and recurrent categories could be grouped. This represented the complete range of explanations in the data set. The listed reasons were purely descriptive, and at this stage the researcher only tried to summarise what was actually written in the open ended replies. This made it easier to see the range of potential categories, and how some could be refined or collapsed.

5.4.2 Categorisation of reasons

At the second stage of analysis Ritchie and Spencer (1994) explain that "... the analyst returns to [the] research notes, and attempts to identify the key issues, concepts and themes according to which the data can be examined and referenced. That is, she or he sets up a thematic framework within which the material can be sifted and sorted." In the present analysis we had already decided on the thematic framework, i.e. "scenarios precipitating inpatient death". The second stage of analysis rather represented a means of labelling and sorting the components within this framework.

The listing of explanations on the word processor during step one now facilitated the reviewing and grouping of reasons into categories which seemed to share underlying features. Table 5.2 shows the outcome of steps one and two. Words in capital letters and/or bold represent the categories into which the explanations were grouped. The words not in bold are the explanations which make up the categories. The table lists the full range of explanations for admission to inpatient care given by GPs, district nurses and informal carers which were obtained from scrutinising the data.

TABLE 5.2: CATEGORISATION OF REASONS FOR INPATIENT DEATH

PATIENT CONDITION	PROBLEMS WITH INFORMAL SUPPORT
brain tumour	**Carer "unable to cope"**
cancer	carer "unable to cope", unspecified
incurable illness	
	Carer tiredness
PATIENT PHYSICAL CARE NEEDS	carer exhaustion
	carer need for respite
generally high care needs (up to 24 hours)	
immobility	**Carer psychological problems**
increasing disability	stress and distress over situation
assistance from two people required	emotional strain
complex care needs (specified)	carer fear of death at home
	anxiety
CLINICAL EVENT OR PROCEDURE	
	Practical – lack of informal support
investigation	disabled carer
diagnosis	elderly carer
treatment	patient alone
transfusion	no informal cover
	family work commitments
sudden event (heart attack, haemorrhaging)	family geographical distance
emergency	
fitting	**Family dynamics**
	family social problems and/or tensions
chest infection	patient not wanting to be with family and vice versa
symptom control	
assessment	**Unsuitable home situation**
drug adjustment	young children
	poor or unsuitable housing
deterioration	
	PREFERENCE FOR INPATIENT CARE
PATIENT PSYCHOLOGICAL PROBLEMS	
	by family
depression	by patient
worry about being a burden	
fear of dying alone	**PROBLEMS WITH PROFESSIONAL SUPPORT**
distress over situation	
anxiety	lack of HAH
	lack of nursing/ social service
MISCELLANEOUS	too little support in general
	lack of 24 hour care
GP decision	lack of night care
late diagnosis	period of care too limited
patient/ carer refusing help	delay in organising care
patient having "difficult personality"	lack of specialist care
home care not viable option	geographical distance
	poor continuity of care

The division of PROBLEMS WITH INFORMAL SUPPORT into sub-categories illustrate how the research question to an extent influenced analysis at this stage (i.e. to what extent would patients have benefited from added home care). For instance, **Carer tiredness** and **Practical - Lack of Informal Support** are both situation in which added home support may have helped. However, **Carer psychological problems** and **Family Dynamics** represent more complicated situations in which a straightforward introduction of home care may not have been useful, while **Unsuitable home situation** suggests home care would be inappropriate.

PREFERENCE indicates that inpatient care and/or death was the choice of the patient or carer. An important issue for our analysis is the basis for this preference. Was it a genuine preference for inpatient care given ideal home circumstances, or was it a result of deficiencies in home support? If it was a genuine preference for inpatient care, attempts at facilitating home death would be inappropriate. However, if there are indications that the "preference" was caused by insufficient support in the home, added home care may well have helped. Our interpretation of PREFERENCE therefore depends on its context.

It was already clear from the categories in Table 5.2 that the explanations given were not independent of each other. For instance, **Carer Tiredness** is likely to be related to patient's CARE NEEDS and PROBLEMS WITH PROFESSIONAL SUPPORT. The interpretation of one explanation can furthermore depend on the context in which it occurs, e.g. PREFERENCE. The categories used reflect the manner in which the respondent chose to explain an inpatient admission, but different respondents may have chosen to express the same situation in different ways. A consideration of explanations also highlighted a difference between inpatient death as a result of end stage admission or as a result of failure to achieve discharge from hospital due to e.g. patient deterioration or lack of home support.

Ritchie and Spencer (1994) note how the researcher will draw upon *a priori* issues as well as emergent themes when constructing the coding framework. Previous research has identified symptom control issues and breakdown in, or lack of, home support as reasons for inpatient admissions (Doyle, 1980, Wilkes, 1984, Dunlop et al, 1989, Herd, 1990, Lubin, 1992). In the present analysis symptom control was subsumed under

CLINICAL EVENT OR PROCEDURES (Table 5.2) as it was not clear at this stage of analysis how it differed from other items within this category. Several of the events, e.g. assessment, are likely to have been precipitated by a symptom control problem. The categories are more fine grained than that of past research in relation to informal support, however. This may be due to the content of the data available or the focus of analysis. For instance, **Family dynamics**, **Unsuitable home situation** or PREFERENCE do not feature in previous research. Such information may only be derived from respondents who know the patients and their home situation well. As we know nothing of how categories were formed in previous research, we cannot assess whether a different focus of analysis also played a part.

5.4.3 Indexing

Ritchie and Spencer (1994) define their third stage of analysis, indexing, as "the process whereby the thematic framework or index is systematically applied to the data in its textual form", i.e. the text is labelled according to the derived categories. This is purely a pragmatic process to aid further analysis, i.e. ".. a mechanism for labelling data in manageable 'bites' for subsequent retrieval and exploration". Ritchie and Spencer (1994) note how categories should not be over-elaborate in detail at this stage as there is a need to retain an overview of the categories. The text segments were labelled using categories shown in Table 5.2 with the help of QSR NUD*IST 4 analysis software (QSR NUD*IST 4 User Guide, 1997).

Below is an example of the explanations provided by the GP, district nurse and carer for one case.

Case no. 382

DN: *"Symptom control, confusional state, family tired."*

GP: *"Difficulty with sedation/analgesia at home"*

CARER: *"My wife was in because of her condition and the care she needed"*

The associated coding was as follows: CLINICAL EVENT: "*symptom control, confusional state*", "*difficulty with sedation/ analgesia at home*"; PATIENT CONDITION: "*her condition*"; CARE NEEDS: "*the care she needed*"; **Carer tiredness**: "*family tired*".

Ritchie and Spencer (1994) note that the application of an index involves "making numerous judgements as to the meaning and significance of the data". However, in the present analysis the simple nature of our data and the descriptive nature of the index categories reduced the amount of interpretation required. The explanations listed in Table 5.2 very nearly represent the range and limits of each index category, due to the brevity of explanations and the limited number of cases (80) for analysis. In certain cases it was, however, difficult to decide on the appropriate category.

For instance, both the following statements were coded as CARE NEED although they could also have referred to a lack of professional support. *"It was impossible to give her the attention she needed at home."* (Ref no 206, Carer). *"Needed 24 hour nursing care."* (Ref no 343, district nurse). Furthermore, *"loss of use of arms and legs* (Ref no 238, Carer)" was also coded as CARE NEED, but could be seen as CLINICAL EVENT (deterioration). However, instances of "immobility" were already coded as CARE NEED, and such loss of mobility was assumed to be directly associated with the care needed by the patient. Finally, some statements defied coding within the developed categories. *"Looking after her in a private home had ceased to be a viable option."* (Case no. 407, Carer) had to be assigned to the "miscellaneous" category.

5.4.4 Overview of the data set and comparison of respondent groups

Table 5.3 gives an overview of the data set following the indexing of the total body of text for the study. This serves two purposes. First, it shows the extent to which researcher's classifications are able to account for the data set. The degree of comprehensiveness has a bearing upon the trust the reader can place in such forms of analysis (Seale and Silverman, 1997). If only a small part of the data set is covered by the coding categories, the rigour of the analysis and the validity of the categories used may be questioned. However, Table 5.3 shows that a relatively small part of the coded text had to be assigned to the "miscellaneous" category (see Table 5.2 for details of this category).

Second, we aimed to combine the respondent explanations for each case. Some patients only had one respondent explanation and others three, i.e. there were different degrees of "completeness" in the

information available (see Table 5.1). We therefore needed to consider whether GPs, district nurses and carers consistently used different types of explanations. If so, having one respondent group missing could bias our assessment of the case. For instance, if district nurses consistently explained inpatient admissions in terms of insufficient professional help, the presence or absence of the district nurse account may influence our assessment of the likely benefits of added home care in each case. Thus the data overview enabled us to assess whether there were any obvious biases within any respondent group.

While overall patterns can be assessed, it would be inappropriate to test whether there was a statistically significant difference in types of explanations used between respondents, as the assumptions underlying data collection and analysis were different to those required for statistical analysis (e.g. the categories are interrelated, definitions are not necessarily clear cut, more than one explanation may apply to a given situation). Similarly, the frequency with which a category is mentioned does not necessarily indicate its importance within the data set.

Patient CONDITION was mentioned by 15 of 50 carers compared to none of the district nurses and GPs. Thus it appears that the condition itself was perceived as sufficient explanation for inpatient admission to many lay carers.

Respondents also appeared to differ in their use of "carer unable to cope" explanations. District nurses were three times and GPs over five times as likely to use this category as carers. It is perhaps unlikely that a carer would express that "I was unable to cope" as this seems to place the "blame" of an emotionally charged outcome squarely in their court. Health professionals may on the other hand use this term as a rationalisation, which perhaps in itself does not explain much. Otherwise carers were similarly likely to use PROBLEMS WITH INFORMAL SUPPORT categories as were district nurses and GPs.

Table 5.3: Number of response per category by respondent group (percentage of respondents mentioning each category).

	District nurse	GP	Carer	Total mentions
CONDITION	0 (0)	0 (0)	15 (30)	15
CARE NEED	13 (17)	8 (14)	9 (18)	30
CLINICAL EVENT	40 (50)	28 (48)	20 (40)	88
PATIENT PSYCHOLOGICAL	4 (5)	6 (10)	2 (4)	12
INFORMAL SUPPORT:				90
- Carer "unable to cope"	9 (12)	13 (22)	2 (4)	24
- Carer tired	4 (5)	3 (5)	2 (4)	9
- Carer psychological problem	6 (8)	8 (14)	6 (12)	20
- Practical – lack of informal support	11 (14)	5 (9)	3 (6)	19
- Family dynamics	5 (6)	4 (7)	2 (4)	11
- Unsuitable home	4 (5)	2 (3)	1 (2)	7
PREFERENCE	15 (19)	6 (10)	3 (6)	24
PROFESSIONAL SUPPORT	18 (23)	13 (22)	12 (24)	43
MISCELLANEOUS	10 (13)	6 (10)	5 (10)	21
Number of respondents	78	58	50	

Finally, the district nurses were over three times as likely as carers to state that inpatient care was preferred, while GPs did not particularly differ from carers. Again it may be difficult for carers to state that they preferred care to take place outside the home, as this may imply lack of effort or will on their part. If some cases have only professional responses associated with them, there may therefore be a slightly greater tendency to attribute inpatient death to preference or carer inability to cope. There were otherwise not sufficiently clear differences between respondent groups to merit attention. Most important for our analysis, respondents were very similar in terms of citing lack of professional support as an issue.

5.4.5 Creating a model of interrelationships between explanations

A model was created to illustrate the likely relationships between explanations within the data set. Such model building anticipates Ritchie and Spencer's (1994) final stage of framework analysis of mapping and interpretation. However, the creation of a model at this stage was helpful in structuring the subsequent analysis, assess the coherence and likely validity of the accounts, and may also aid the presentation of the analysis to the reader.

A model of explanations enabled us to see more easily that there are some configurations of explanations we would expect and others we would not expect to occur. As noted, there was a need to combine the explanations provided by different respondents about one and the same case. We needed to acknowledge that these explanations related to the same situation, and their combination enabled us to gain as complete a picture as possible for each case, within the limits of the data set. A model of interrelationships between explanations helped us see whether explanations appeared complementary or may contradict each other. Furthermore, from a theoretical viewpoint reasons behind inpatient admissions should be viewed as a system of variables rather than a single factor. An inpatient admission is likely to be the result of sequence of events or a set of interrelated causes.

Specific to our analysis, the model helped us consider whether the situations in which insufficient home care was mentioned appeared different (formed different configurations) to those in which it was not. If there are systematic, plausible patterns, we can be more confident that we have truly identified cases for whom added home care may have made a difference versus those for whom added support would be of little use or relevance. However, if mention of home care deficiencies appears to occur in "contradictory" configurations, we will necessarily be less confident about our data.

5.4.6 The content of the model

Figure 2 shows a model of how reasons for end stage inpatient admissions may interrelate. Note that this is a model of respondents' explanations. It is not a model of the "true", underlying components determining place of death. If the model were to map out the underlying components determining place of death, a number of things are likely to be missing, e.g. communication, awareness, spiritual faith, the sheer awfulness of dying, loss.

The model in Figure 2 takes a simple dichotomy as its starting point. It assumes that terminal illness gives rise to a number of problems or needs (dependency, symptoms, distress) which have to be dealt with in the

home, if home death is to be achieved. Whether these needs are met, depends on the resources available in the home (informal care and professional support). The level of problems or need will influence the level of resources required, and if needs become too great or complex, it may no longer be feasible or ethical to sustain home care.

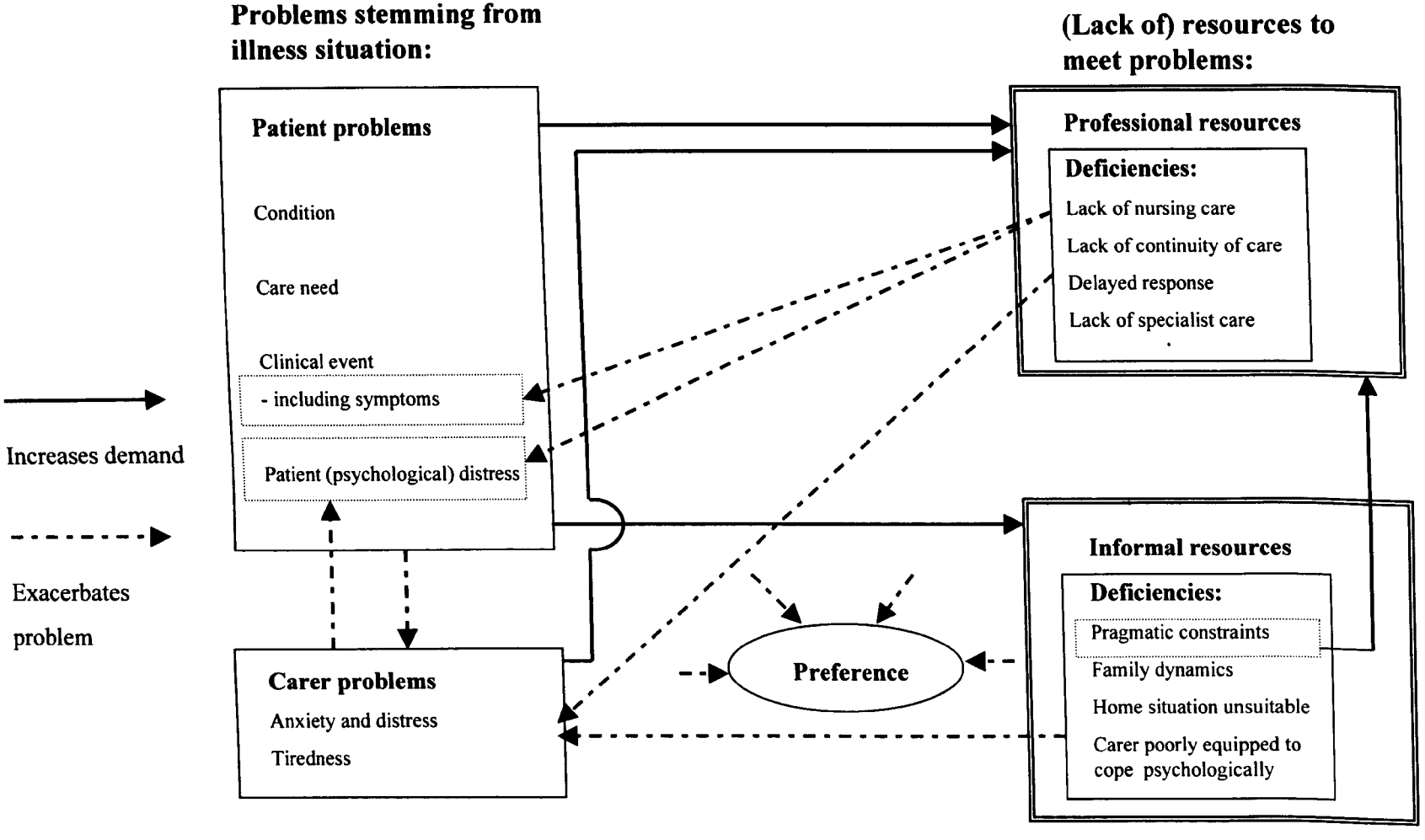
On this simple basis respondents' explanations for inpatient admissions could be seen as being of two types:

1) Problems stemming from the illness situation. These may be problems relating both to the patient and the carer (left side of Figure 2).
2) Lack of resources available to meet the problems stemming from the illness. These may be informal or formal (right side of Figure 2).

It is assumed that patient problems increase the demand on professional and informal resources. If there is a practical lack of informal resources, the demand on professional resources is even greater.

If there are deficiencies in professional resources, these are unlikely to have an impact on patient condition or care need (the patient will still require 24 hour care whether forthcoming or not). However, lack of professional support may exacerbate patient symptoms and psychological distress, and it is clearly likely to exacerbate carer distress and tiredness. It is assumed that professional support would not remove carer psychological distress and tiredness. Good support can probably only maintain it within bearable levels.

Figure 2: Model of interrelationships between types of explanation



In the model "informal resources" are the resources available from the outset to meet patient needs, while "carer problems" represent the problems which develop out of the illness situation. It is assumed that some deficiencies in informal resources can be counteracted by professional support. If there is a simple practical lack of informal support, this should be amenable to home support. However, simply adding home care is unlikely to improve the situation if there is family conflict, an unsuitable home situation, or perhaps, if the carer from the outset is poorly equipped to cope psychologically with death at home. Rather than increasing demands on professional resources, these items suggest that care at home may be inappropriate.

"Carer problems" can be exacerbated by increased patient problems and by deficiencies in professional support and informal resources. A tired or anxious carer in turn requires more support from the professional services. In reality carer problems and informal resources are closely interlinked: as the carer grows tired there are fewer resources to deal with the patient's illness. However, for the sake of our analysis, when trying to assess whether professional home support would make a difference, the distinction was perceived to be a useful one.

The location of "preference" in the model implies that preference for inpatient care can be an independent choice made by the patient or carer, or a "choice" which is forced upon them because of deficiencies in home care, informal or professional, or the scale of patient problems. If there is a true preference for inpatient care, the issue of home care support is less relevant. If the preference stems from the scale of patient problems, home care may be irrelevant, but one needs to ask whether patient problems may have been ameliorated by added support. However, if the "preference" for inpatient care stems from insufficient home support, the preference may have been prevented from occurring in the first place through increased professional home support.

Carer "unable to cope" does not feature in the model. Due to its unspecified nature it could either refer to the carer's general resources to cope or the carer becoming too exhausted or overwhelmed over time from the illness situation. It therefore relates to the bottom part of Figure 2, but was not firmly placed either side.

Based on the links in the model, we would expect explanations of insufficient professional home support to occur in combination with certain explanations. Any of the categories under patient problems, perhaps particularly care need, are likely to occur together with explanations of deficiencies in support. There may, however, be individual items under clinical events or procedures which would require inpatient care, and therefore not occur with mentions of insufficient home support.

We would expect explanations of a practical lack of informal support to be mentioned together with deficiencies in professional home support. However, explanations mentioning family dynamics, unsuitable home situation or poor psychological resources in the carer (fear of death at home) should not occur together with professional support, as straightforward addition of home care is less likely to have a bearing on these problems.

We would expect explanations of deficiencies in professional home support to be mentioned with carer tiredness and distress arising from the illness situation, as added home care should have a role in reducing or preventing these problems.

Conversely, if deficiencies in professional home support are not mentioned, we would expect the reasons for inpatient admissions to be such that home support is likely to have had little or no impact, e.g. those in which there was a genuine preference for inpatient care, presence of unsuitable home conditions, family conflict, clinical events requiring inpatient care, or the care needs were so great and the level of informal resources so poor that home care did not appear feasible.

Finally, if patient and carer have a genuine preference for inpatient care, one would not expect the level of home support to be mentioned, as it would probably not be wanted. However, inpatient care may also be a "preference" which is forced upon patient and carer because lack of support and high care need make home care an undesirable alternative. Thus, as noted, our interpretation of PREFERENCE depends on its context. This leads to some risk of a circular argument in interpreting this category, and care needs to be taken to avoid this where possible.

5.4.7 Charting and mapping the data: investigating patterns with and without home care

In this section a distilled summary of explanations for inpatient deaths for each case is provided. Cases are grouped according to the type of explanations they display and the resulting groups described and considered in light of the model (Figure 2). This corresponds with Ritchie and Spencer's (1994) fourth stage of analysis, charting, in which "the analyst needs to build up a picture of the data as a whole, by considering the range of attitudes and experience for each issue or theme". Charts are created so that the data set for each case can easily be reviewed and only a distilled summary of the data is entered on the chart. However, the material presented also constitutes Ritche and Spencer's (1994) final stage of analysis, in which key characteristics of the data are pulled together and the data set as a whole is interpreted. We compare and contrast the groups of explanations, in particular cases with and without mention of deficiencies in home care, and consider if these represent different configurations or structures of explanation.

Cases were first grouped on the basis of the extent to which inpatient death was attributed to insufficient professional home support. Three groups of cases were formed:

- cases for which one or more of respondents identified lack of professional home support as the reason for inpatient death.
- cases for which respondents' explanations suggested there was a lack of professional home support, but without inpatient death being directly attributed to this
- cases for which inpatient death was purely attributed to factors other than lack of professional home support

The three groups of cases are presented below. In each section a chart or table gives an overview of the response categories for each case. The accompanying text first gives an overview of each section followed by the examples on which it is based.

For the text accompanying the charts the following conventions apply. Quotation marks and italics mark directly quoted text. Dots within quotation marks show omitted detail which was not relevant to the argument. Parentheses containing text within quotes are replacements of, or additions to, original text without change in meaning. For example "*Joe Bloggs*" would be replaced by *"(the patient)"*, and a grammatical component, e.g. *(was)* may be inserted to make the quote readable in the presented context. The codes DN, GP or CR show whether the source of a quote or explanation was the district nurse, GP or carer respectively. Three digit numbers show the case to which the text refers. While cases are grouped in the text so that cases with similar features can be discussed together, cases are listed with their reference numbers in sequential order in the tables for ease of location if the reader wishes to refer to the table from the text. Each section first provides an overview, including an assessment of whether the combination of explanations appear plausible in light of the model (Figure 2). This is followed by a detailed presentation of cases with accompanying quotes.

5.4.7.1 Inpatient death attributed to lack of professional home support

There were 21 cases within this group. Eight of these were controls. Table 5.4 displays the case charts. There appeared to be very few "incongruent" configurations of explanations. Accounts of insufficient professional home support was only combined with unsuitability of home conditions and anxiety about home death in one case (274), and with family conflict in one case (351). Preference for inpatient care was mentioned in three cases, and in two cases (291, 327), possibly all three (274), preference may be attributed to lack of support. On the whole it appears that the clinical events or other patient problems mentioned either could have been counteracted with more home support or they were not a direct cause of inpatient death. Carer inability to cope or tiredness appeared to stem from lack of support. Only for two cases (198, 339) do district nurse and GP explanations appear in conflict, as one emphasises insufficient home care and the other symptom control needs which may have required specialist care. Thus we are largely observing combinations of explanations which appear plausible in light of our model. Cases are discussed in detail

below with accompanying quotes. For ease of presentation cases are grouped according to whether home care is combined with patient problems or with problems with informal support.

Table 5.4: Cases for which one or more of respondents identified lack of professional home support as cause of inpatient death; (c) control

Ref no	DN	GP	CARER
196 (c)	Supp, Clin, Care need	Clin	
198	Supp	Clin	
239	Clin	-	Supp
254 (c)	Cpract	Supp	
266 (c)	Supp, Cpract	Clin, Misc	
273 (c)	Clin	Supp, Clin	-
274	Pref	Supp, Ppsych, Chome, Ppsych	Supp
282	Supp, Cutc, Ctired	Supp, Cutc	Supp, Ctired
286	Supp, Cutc, Care need, Clin		Supp, Cond
291	Supp, Clin	Supp	Pref
296 (c)	Supp		
306	Supp, Clin, Misc		
308 (c)	Supp, Clin		
327 (c)	Supp, Clin	Supp, Pref	Supp?
339	Supp, Care need	Clin	
343	Supp	Supp, Clin	Supp, Clin
351	Supp, Cfam	Supp, Psych, Care need	-
366	Cutc		Supp, Clin, Cond
380	Supp	Supp, Clin	
420	Cutc, Clin	Misc (Lack of continuity in GP support)	Supp, Care need
435 (c)	Supp	Cutc	Supp, Clin

KEY: **Care need**: patient physical care needs; **Cfam**: family dynamics; **Chome**: unsuitable home situation; **Clin**: clinical event or procedure; **Cond**: patient condition; **Cpract**: carer practical – lack of informal support; **Ctired**: carer tiredness: **Cutc**: carer unable to cope; **Misc**: miscellaneous; **Ppsych**: Patient psychological problems; **Pref**: preference; **Supp**: problems with professional support; - : not possible to code (e.g. "don't know")

- Lack of professional support mentioned as only reason for inpatient death

Only for one patient was inpatient death explained purely in terms of lack of professional support (296), and the deficiency lay in "*lack of night care* (DN)". Thus added home support should have been beneficial in this case. However, we only have a district nurse's account and no information on the patient or carer situation.

- Accounts mentioning insufficient professional support combined with patient problems

There were ten cases in this group (196, 198, 239, 273, 291, 308, 327, 339, 343, 380).

For four cases the problem was one of discharge from hospital (239, 273, 308, 380). Clinical reasons for admission were mentioned: e.g. the patient deteriorated (239: DN, 273: GP), was admitted for "*investigation and care and appropriate treatment* (308, DN)", "*investigation for painless jaundice* (380, GP)", or "*cardiac and respiratory complications* (273, DN)". For 239 and 273 the situation was further complicated by a late diagnosis during final hospital stay. However, the key issue for home death was failure to arrange home services for discharge. There was either a lack of care, as in "*.. support services unavailable* (273, GP)" or "*The liaison sister from hospital rang to ask if we could give 24 hour nursing care, unfortunately we could not, ... HAH .. were unable to take him on* (308, DN)", or services could not be arranged quickly enough, as in "*... dad might have been happier had his coming home arrangement gone quicker and dad could have come home earlier* (239, CR)" or "*... I was contacted ... about the possibility of him coming home to die with 24 hour cover from HAH .. he died before it could be set up* (380, DN)". It is clear from the responses that neither 308 nor 380 had had prior contact with the district nurse.

For case 196 availability of 24 hour care at short notice might have enabled the patient to remain at home. However, there may also have been sense of urgency to "do something" : "*She survived 24 hours at home after massive M.I. ... Because of the high need for 24 hour care and the remote chance this lady might survive, the GP admitted her to hospital after 24 hours. However, if Hospital at Home had been available she might have been able to stay at home. I doubt that she would have recovered as she had had a heart problem for some years* (DN)". The GP only mentions the myocardial infarct and notes "*improving by 8am next morning therefore admitted*".

For 198 and 339 the GP and district nurse appear to be at odds in their explanations. The district nurse cites inability "*to get nursing/ social service care package* (198)" or "*need for 24 hour care* (339)", with no

mention of symptoms. Conversely the GP only mentions symptoms; *"vomiting became uncontrolled* (198)" or "*unable to swallow - choking on saliva* (339)". Whether added home support would have helped depends on whether one gives emphasis to the district nurse or GP account, and the extent to which experienced palliative nursing care could have helped prevent/ ameliorate the symptoms. There is no mention of attempts to obtain expert advice in the community.

For the remaining cases added home support was likely to have counteracted the clinical factors mentioned. There was a lack of 24 hour care (343, DN,CR, 291, DN, 327, DN), night nursing (343, GP) or nursing and practical support in general (291, GP, 327, GP). Such support may have overcome "*Difficulties in managing breathless nights and distress* (343, GP)", "*crises when they arose* (291, DN)", "*difficulty nursing at home* (327, CR) or "*condition deteriorat(ing)* (327, DN)". In fact 343 "*was home (from hospital) three days before death and had to go back into hospital as the nurses could not give 24 hours care (and she was very distressed*) (CR)". For 291 and 327 the carers state a preference for inpatient care, but apparently after it was clear that HAH would not be available (327, DN) or "*to make (the patient) more comfortable* (291, CR)". Both for 291 and 327 problems were compounded by difficulty in obtaining care during Christmas Holidays. It is therefore possible that the stated preference stemmed from lack of adequate support in the home, rather than an *a priori* preference for inpatient care.

- Accounts mentioning insufficient professional support and problems with informal care

There were six cases in this group (254, 274, 282, 366, 420, 435).

In the case of 282 the carer apparently became exhausted and unable to provide care due to lack of professional support. ".. *Patient was let down when promised night cover ... carer .. was not able to go home and was exhausted from lack of relief from care* (DN)"; "*(the carer) could have coped better had she had some relief at night but was let down on a number of occasions* .. (GP)"; "*Insufficient nursing care ... I was physically and mentally unable to 'manage' for what may have been another four or five days* (CR)".

In three other cases (366, 420, 435) it also appears that the carer's "inability to cope" was related to lack of professional support. For both 366 and 420 the district nurse states the carer was unable to cope with discharge (366) or sudden deterioration (420). However, the carers' responses suggest they felt they would have managed had they had sufficient professional support. For 366 the carer states "*I would only have liked my husband home as I loved him so much, but they couldn't get 24 hour care ..* (366)". For 420 the carer explains "*.. emergency doctor on Sunday afternoon (date) was unable to obtain Marie Curie or BNA nurse the night of (date) ... 20 hours a week Marie Curie totally inadequate for a patient dying of cancer. One person (me), the patient's wife cannot single handed look after a patient requiring 24 hour a day care* (420)". For 435 the GP cites "*inability of husband to look after patient at home*", but both the district nurse and carer puts this down to lack of support: "*not enough care input to be able to support husband* (DN)"; "*I would have liked to seen (sic) more help in the end so I could have had her home* (CR)".

Case 274 is less straightforward, in that the district nurse states that the patient wanted to go into hospice and the GP that there was "*family anxiety about death at home, young children in the house, patient's desire not to be a burden*". Thus this appears to be a case inappropriate for home care. However, the GP notes there was both less medical support from surgery and poorer communication between the GP and district nurse team than usual due to geographical distance and health authority borders. Thus the case may have been poorly managed from the start and lack of support may in part have given rise to the above preferences and anxieties. Furthermore, the carer attributes admission directly to a potential lack of care: "*my mother went into Arthur Rank (hospice) as it was xmas and nurses might be difficult to obtain.*" This case did have HAH prior to admission but for two days only.

For case 254 the district nurse notes an absence of constant informal cover as the patient lived alone, while the GP cites inability "*to get night time 'carer'*" for patient. Although lack of informal care would make home care more difficult, the patient may have benefited from added professional home support.

- Accounts mentioning insufficient professional support in combination with both patient and carer problems

These three cases (351, 266, 286) appear more complex, but there appears to be a clear indication that more professional support would have been beneficial according to accounts.

For 351 the district nurse reports that the patient lived alone with no family support due to family conflict, and thus "*needed ongoing 24 hour care for indeterminate time - not available in the community*". In this case family conflict would not have interfered with professional care. The GP cites care needs, but also notes that "*Pain relief etc - no problem at home. Loneliness with fear - a major problem. Dying patients need 24 hour company*". For 266 the district nurse states that the patient was "*unable to have enough support when needed - no relative*". The GP cites deterioration and "*medical condition*", but adds *"(the patient) had a difficult personality and the care provided was as much as possible under the circumstances*". Both 351 and 266 probably would have benefited from additional professional support.

While case 286 had high care needs, responses suggest that it may have been possible to maintain her at home. "... *she needed 2 persons to handle her ... This type of care was not available at home. If we had night cover available, it might have been possible for this lady to die at home. But it was a high nursing care problem* (DN)". Under these circumstances the "*Daughter (was) unable to cope with (the patient's) 24 hour care* (DN)". The carer notes *"(the patient) needed 24 hour care. In three weeks of care I had only three night nurses*".

Case 306 does not directly fit the above classes and is unusual in that it represents a conflict between GP and district nurse in decision making. The patient was reportedly admitted following sudden deterioration, but the "*Decision (was) made by GP without consulting us and against family's wishes. Hospital at home would have been ideal if client had stayed at home* (DN)".

In summary, according to respondents' accounts most of the above cases would probably have benefited from more home support or more rapid mobilisation of such support. We cannot assess whether lack of home support really was the key precipitating factor in inpatient admission, however, and thus whether admission could have been prevented through better provision. There are particularly doubts about this where there appeared to be conflict between GP and district nurse accounts (198, 339), other factors may have made home care inappropriate (274), care needs may have been long term (351) or difficulties in introducing care may have existed (266). However, these cases may still have derived some benefit from added home support.

5.4.7.2 Accounts mentioning lack of home support, without death in inpatient care being directly attributed to this

There were eight cases in this category (215, 226, 238, 261, 284, 318, 376, 400). Three of these were controls (Table 5.5). Many of these cases (226, 261, 284, 318, 376) combine explanations from three areas of the model (i.e. patient problems, problems with informal care and lack of professional support). This may simply be due to the amount of detail respondents chose to include, but the situations on the whole appear more difficult to manage than cases in the previous section. Table 5.5 summarises responses and types of explanation.

Table 5.5: Cases for which respondents explanations suggest a lack of professional home support, but without inpatient death being directly attributed to this; (c) control

Ref no	DN	GP	CARER
215			Supp, Clin
226 (c)	Supp, Cpract	Supp, Clin, Cutc	
238	Clin, Misc		Clin, Care need
261 (c)		Supp, Ppsych, Cutc, Ctired	
284 (c)	Supp, Ppsych, Cpsych, Clin, Cpract	Supp, Clin	Clin, Ppsych, Cpsych
318	Clin, Pref	Supp, Cutc, Care need	Supp, Clin
376	(DN "not involved")	Clin, Cutc	Supp, Care need
400	Supp, Clin	Clin	

KEY: **Care need**: patient physical care needs; **Cfam**: family dynamics; **Chome**: unsuitable home situation; **Clin**: clinical event or procedure; **Cond**: patient condition; **Cpract**: carer practical – lack of informal support; **Ctired**: carer tiredness: **Cutc**: carer unable to cope; **Misc**: miscellaneous; **Ppsych**: Patient psychological problems; **Pref**: preference; **Supp**: problems with professional support; - : not possible to code (e.g. "don't know")

On the whole the combinations of explanations appear plausible in light of the model. Within this section insufficient professional support does not occur together with unsuitable home conditions, family conflict or preference for inpatient care. The situations implied appear more difficult in terms of symptoms, distress, carer complications or exhaustion than in the previous section. Nevertheless, it appears that added home support could have helped prevent or ameliorate the effects of these variables.

Case 376 suggest that the patient and carer were poorly supported. The district nurse was not involved, and the carer complained they were unable to get "*Macmillan nurses*" until it was "*too late*", due to confusion arising from being on the border between Cambridgeshire and Suffolk. The GP attributes admission to "*intractable cough*" and the carer's inability "*to cope with stress of distressed husband*". The carer, however, simply puts admission down to a practical nursing problem: "*Very difficult to get (the patient) in and out of bed on my own*". The carer would therefore perhaps have "coped" if supported. Earlier Macmillan involvement may also have aided symptom control as the GP felt "*maybe some expert medical advice would have helped*".

While clinical reasons for admission are cited for case 284 (*"coffee ground vomit* (DN)"; "*symptomatic care* (GP)", *inability to eat* (CR)), a key factor appears to be anxiety, both "*patient anxiety at being alone at night* (DN)" and carer anxiety over the patient's situation (DN, CR). The GP also notes a need for "*social care*". The clinical factors might have been managed at home and the anxieties reduced through professional home support. The district nurse notes that HAH help had been requested but that the patient was a control.

Case 226 would probably also have been able to benefit from added home support. The carer broke her leg three weeks before the patient's death and two weeks before admission to hospice. Upon referral the patient came up as a HAH control. The district nurse states that the patient was "*admitted to relieve pressure at home*", and notes "*domestic support*" was requested but not available. The GP cites "*symptom control and nursing care*" as reasons for admission.

Two cases probably could have benefited from more support according to the district nurse, but there appears to have been resistance to accept added care (238, 400). For 400 there was a last minute admission "*for assessment, ? transfusion* (sic) *and pain control* (DN)" and "*reassessment* (GP)". However, the district nurse notes that "*patient and family only wanted support from GP and DN + social care from Social Services - they felt adequately supported by family and care team .. although care team felt increased input may have been of benefit especially to carer*". For 238 problems of "*symptom control* (DN)" and "*Breathlessness, loss of use of arms and legs* (CR)" may have been managed at home. The district nurse adds, however, that "*This lady was quite difficult to help i.e. refused quite a lot of support even to the extent of turning down help with DN present in the house*". Case 238 and 400 again illustrate that although there may be a need for support and help available, there may be difficulty in introducing care (Grande et al, 1997).

Cases 215 and 261 indicate extreme exhaustion in the carer which may have been prevented through earlier support, although last minute measures probably would not have helped. For 215 the admission, for a heart attack, was probably unavoidable. However, prior to this the carer writes "*Eight years of cancer, no support at all .. I had months of night and day nursing alone without help, until I was worn out mentally and physically ..*". Discharge from hospice was attempted through referral to HAH nine days before death. However, if the carer was mentally and physically exhausted after months of coping on her own, she may have been unable to take the patient back after three weeks' respite. Case 261 was referred to HAH 45 days before death but became a control. The GP notes that the carer "*became very tired and exhausted and sadly died six days after her husband*". Patient depression complicated the picture. For an additional case, 318, the GP notes that patient and carer were not coping well due to pain and immobility, but that "*more nursing care might have helped*". The carer also cites inability to "*give adequate care at home*". The district nurse emphasises that the family requested admission to hospice due to finding deterioration in the patient's condition distressing. The carer also comments on not realising how close to death the patient was and the potential side effects of morphine. There is therefore a considerable degree of distress indicated, but which may have been ameliorated by more nursing care and preparation of family. Records show there was some HAH input for two days just before death prior to hospice admission, but this may have been too late to

change matters. Thus early introduction of support, not just support *per se* may have been the issue for the three last cases (215, 261, 318).

In summary, it appears that most of these cases might have benefited from added home support, according to the explanations provided. However, location of death itself did not appear to be attributed to lack of home support. Several other factors complicated the picture and added home care may not have had any impact on place of death. Case 215 and 261 would have required help far earlier if it was to make any difference in this respect. Problems of refusal may mean that additional care may not have been possible for case 238 and 400.

5.4.7.3 Inpatient death attributed to factors other than lack of professional home support

This was a large group of 49 cases. In these cases respondents did not at all attribute inpatient deaths to lack of home support. The analysis considered whether the patient and informal care problems mentioned and the situations described were different from the cases in which lack of home support was mentioned. In particular it considered whether these situations implied that home support would not have helped, i.e. that the lack of mention of home support was not purely coincidental.

For ease of presentation we group cases according to whether the explanations mentioned patient problems only, consisted of a combination of patient and carer problems for each case, or emphasised problems with informal care. As previously, an outline is provided first followed by more detailed examples of cases with quotes.

- *Emphasis on patient problems only*

There were 20 cases in total within this section (Table 5.6). Overall the situation surrounding these deaths suggests that added home nursing support may have made little difference. It therefore appears that the lack of mention of home support in these cases is not due to coincidental omission or emphasis. In three cases

there was a preference for inpatient care which appeared unrelated to insufficient home support (243, 262, 415). Care need was only mentioned among the patient problems in one case (422). Otherwise inpatient death was due to clinical events which probably would have been difficult to change through a simple introduction of home support. When there was mention of carer's inability "to cope" (362), psychological problems (314) or support (225, 281), this appeared not to be directly related to death occurring as an inpatient.

Table 5.6: Cases for which explanations focus on patient problems; (c) control

Ref no	DN	GP	CARER
225	Clin, (Supp)	Clin	Clin
230 (c)	Clin	Clin, Ppsych	Cond
243	Clin, Pref	Clin	
255	Clin		Clin
259	Clin	Clin	
262	Pref, Clin	Clin	
281	Clin	Clin	Clin (Supp)
292	Clin		
303	Clin		
314	(No DN Contact)	Clin	Clin (Cpsych)
346 (c)	Clin	Clin	Cond
349	Clin	Clin	
359	Clin		Cond
362	Clin	Cutc	Clin
383	Clin	Clin	Clin
408	Clin		
415 (c)	Ppsych, Pref	Ppsych	Cond
422	Clin, Care need	Care need	
429	-	-	Cond
448	Clin		Clin

KEY: **Care need**: patient physical care needs; **Cfam**: family dynamics; **Chome**: unsuitable home situation; **Clin**: clinical event or procedure; **Cond**: patient condition; **Cpract**: carer practical – lack of informal support; **Ctired**: carer tiredness: **Cutc**: carer unable to cope; **Misc**: miscellaneous; **Ppsych**: Patient psychological problems; **Pref**: preference; **Supp**: problems with professional support; - : not possible to code (e.g. "don't know")

In nine of the 20 cases admission appeared to represent an urgency to "do something" which proved futile under the circumstances (225, 243, 255, 259, 281, 292, 314, 383, 408). One should note that this may only have become clear with hindsight, however. In many of these scenarios the patient should in theory have been able to die at home, because the event was part of the dying process and the inpatient admission could achieve very little. However, in practice there was probably considerable pressure to "do something", and

the death at home would often not have been pleasant. For these "last ditch attempts" it would seem logical that the respondent was not concerned with reporting professional or informal care resources, as these would be perceived to have little bearing upon the matter.

Of these nine cases number 243 had pneumonia diagnosed on the last day of life, whereupon the family reportedly wanted admission for IV antibiotics (DN, GP). In four cases symptoms may have been too dramatic or frightening to be "comfortably" managed at home (225, 281, 292, 408): Case 225 experienced uncontrolled fitting (GP, DN) and was sent to hospital two hours before death, in spite of HAH being introduced that same day; case 281 suffered "*haemorrhaging, CVAs and fits* "; case 408 suffered haemorrhaging; case 292 was admitted due to vomiting blood. One further case (255) raises the difficult ethical issue of whether to rehydrate and provide nutrition as life draws to a close, as the patient was admitted due to "*dehydration* (DN)" and "*Cancer of stomach, a bypass to enable him to eat* (CR)". Not to admit patients in the preceding cases would require considerable preparation of carers and specialist support. However, for case 225 the district nurse comments on a lack of Macmillan support, for case 281 the carer notes "*some psychological support would have been extremely helpful during this time*", in case 408 "*all care (was) done by the family* (DN)", and for case 255 the district nurse only "*knew (the patient) for a very short time ..* ". Case 196 in section 5.4.7.1 who sustained a "massive MI" show some similarities to these cases, and there may be some doubt regarding where this case belongs. However, for case 196 the district nurse did express that immediate availability of 24 hour care may have prevented admission, i.e. there was explicit reference to the usefulness of help from existing services.

Finally, in three of the nine cases admission occurred following a sudden event, and again admission may appear futile with hindsight, but presumably did not seem so at the time (259, 314, 383). These patients had all appeared relatively "well" for a period prior to admission. Case 259 suffered a heart attack (GP, DN). A comment from the GP suggested he was not in favour of admission, "*would have been better not to resuscitate aggressively as was done - in view of known cardiac history*". Case 314 was sent in "*as an emergency with heart failure and chest infection*", while 383 had an "*acute exacerbation of symptoms / collapse* (DN)"; "*.. DVT and pulmonary embolus* (GP)" resulting in "*Breathlessness ... distress* (CR)".

A variety of patterns were found for the remaining 11 of 20 cases. Case 448 was admitted for a procedure to provide symptom relief which could not have taken place at home "*right lung filled up with fluid, taken (to hospital) .. to have lung drained* (CR)". He then died a few days after admission.

For cases 346 and 362 the issue was one of discharge home and arrangements had already been made. Home death would have been achieved had the patient not suddenly died: "*suffered a collapse and died suddenly prior to the planned discharge date* (346, DN)"; "*she died very suddenly* (362, DN)". These two cases appear different to the discharge cases in section 5.4.7.1 in that adequate home support was both available and would have been mobilised quickly enough had the patient not died more suddenly than expected.

Patient 262 and 415 apparently expressed a clear preference for inpatient death, and home care would not have been appropriate in these cases: "*Patient's own decision - did not want to stay at home although hospital at home was offered* (262, DN)"; "*Patient's wife died 2 years ago. He was very distressed by this and asked to be admitted to (hospice) where he felt safe and content* (415, DN)".

In two cases the given situation suggests that inpatient death could not have been avoided. However, earlier knowledge of diagnosis or prognosis may have changed the course of events (303, 349). In the case of 303 bowel obstruction was initially misdiagnosed as constipation, and "*this assumption hindered care. Ideally (the patient) should have been sent to (hospital) immediately to obtain satisfactory diagnosis. We weren't in palliative care mode until too late* (DN)". Diagnosis of cancer was obtained during late acute admission (five days before death). Case 349 is less clear, where patient was admitted "*Initially for treatment of hypercalcaemia and dehydration. He then deteriorated and died before discharge* (DN)". The district nurse adds, however: "*There is still not enough info given to community workers: GPs and DNs regarding prognosis and patient awareness of prognosis*", which may imply that the case would have been handled differently if the prognosis had been clearer.

Case 429 is unusual in that it is a matter of definition whether the patient died "at home" or not. HAH records show that the patient had been in a nursing home for six months and that he died there under HAH care. Carer notes that the patient had both "*Parkinsons disease / lung cancer*". If home is defined as outside the institution, the long term care requirements probably means that home death for this patient was not possible.

Two patients were admitted to hospital for clinical reasons and then transferred to hospice (230, 359). Case 230 was admitted for "*assessment of worsening symptoms* (GP)", and thereafter transfer to hospice was most appropriate according to the GP due to "*severe anxiety and difficulty in symptom control*". However, there apparently had been no district nurse involvement. Case 359 had a "*large abdominal mass interfering with bowels, nutrition, mobility with rapid deterioration following initial hospitalisation* (DN)". There is no further information why the patient could not have been discharged home, but the carer does comment that "*I feel sure that everything was done for my wife and myself*". Patient anxiety (230) and the complexity of symptoms or problems (230, 359) may suggest that specialist inpatient care was appropriate.

Finally, in case 422 the emphasis was on the high care need of the patient. "*Patient very heavily immobile and liable to fit* (DN)"; "*Nursing problems, heavyweight hemiplegic man* (GP)". This case may perhaps have benefited from additional home care. However, on the basis of respondent accounts, the patient appears to have represented a greater challenge for home nursing than the cases in sections 5.4.7.1 and 5.4.7.2. There was no information about the professional and informal resources available to meet this challenge, thus it is difficult to reach any conclusions about this case in relation to home support.

In summary, for the cases within this section the reported course of events (225, 243, 255, 259, 281, 292, 303, 314, 346, 349, 362, 383, 408), procedures required (448), patient preference (262, 415) or length of care needs (429) probably meant that added home care would have been of little relevance in influencing place of death. Perhaps case 230, where there was no district nurse involvement, and case 422 may have benefited from more home care, but the accounts provided do not particularly suggest it would have

changed place of death. The complexity and degree of needs may have made inpatient care more appropriate.

- Explanations combining patient problems and problems with informal support for each case

There were 16 cases in this category (Table 5.8). The complexity of the responses is similar to, perhaps exceeding, those of section 5.4.7.2 (in which insufficient home support was implied but not considered a direct cause of death in inpatient care). Thirteen of the 16 cases had patient problems and informal support problems occur together in the explanation of at least one of the respondents. In these explanations respondents often appear to "weigh" these problems against each other. References to patient care needs appear to occur more often (11 of 16 cases, 69%) than in section 5.4.7.1 in which inpatient death was attributed to lack of home care by respondents (five of 21 cases, 24%), and perhaps more often than in section 5.4.7.2 (three of seven cases, 43%). From our model we had expected care needs to be equally often combined with references to both formal and informal support deficiencies. However, patient care needs may be combined more often with informal rather than professional care deficiencies in respondents' explanations because of an implicit recognition that informal carers normally bear the brunt of meeting patients' needs (Anderson, 1987). The data set is small, however, and the differences between sections may be due to random variation.

The responses also differed from those of section 5.4.7.1 and 5.4.7.2 in the presence of other explanation categories. Unsuitable home conditions formed part of the explanations in four cases (206, 263, 329, 305), family conflict in three (252, 326, 407) and preference for inpatient care in five (227, 277, 329, 335, 443), between them covering the majority of cases. These reasons rarely occurred together with explanations of insufficient home care, neither would we expect them to. In accord with our model they appeared more commonly in this section in which insufficient home care was not mentioned. We should note that the preference for inpatient care may in some cases have been a result of the patient's problems rather than an *a priori* belief that inpatient care was better, however.

Table 5.7: Explanations combining patient and carer problems for each case; (c) control

Ref no	DN	GP	CARER
206	Care need, Cpract, Chome	Care need, Cutc	Care need
227	Care need, Pref, Clin, Cpract	Clin	-
241	Clin		Cond, (Cpsych)
252	Clin, Cpsych, Ppsych	Clin, Cfam, Ctired	Clin
263	Care need, Cpsych, Chome		
277 (c)	Clin, Pref	Pref, Cpsych	Cond, Clin
315	Clin, Cutc		Care need, Cutc
326	Clin, Cfam	Clin, Care need, Cfam	Cond, Cpsych
329	Pref, Chome	Clin	Clin, Misc
335	Care need, Clin, Pref, Chome	Cutc?	Pref, Clin
382	Clin, Ctired	Clin	Cond, Care need
384	Care need	Cpract, Ppsych	Cpract
407	Clin, Care need, Cutc, Cfam?		Misc
428	Clin, Care need	Care need, Cpract	
443	Clin, Pref	Clin, Cpsych, Ppsych	
454	Care need, Ctired		Care need, Clin, Cpract

KEY: **Care need**: patient physical care needs; **Cfam**: family dynamics; **Chome**: unsuitable home situation; **Clin**: clinical event or procedure; **Cond**: patient condition; **Cpract**: carer practical – lack of informal support; **Ctired**: carer tiredness: **Cutc**: carer unable to cope; **Misc**: miscellaneous; **Ppsych**: Patient psychological problems; **Pref**: preference; **Supp**: problems with professional support; - : not possible to code (e.g. "don't know")

The balancing of care need versus informal resources is evident in cases 206, 263, 335, 384, 454. Case 206 suffered loss of mobility (GP,DN) which was combined with carer disability and inadequate housing (DN). GP notes that the patient's "*husband was unable to cope despite support*". Case 263 was also immobile and had professional support (HAH). However, the district nurse states "*Emotional strain on family, difficulty of nursing/ coping with (the patient's) immobility in a mobile home. Problem highlighted with number of different nurses and waiting for nurses to arrive as they were not sure they would find the place ...*". While better continuity of care may have helped, this was clearly a difficult nursing situation. For both 384 and 454 the district nurse stresses that the patient required assistance from two people, while it is clear that there was little informal support available: "*..patient lived alone ... lack of family input* (384, GP)"; ".. *I was working full time* (454, CR)". Provision of constant help from two professionals would be quite difficult in the home. Case 335 had particularly difficult nursing needs which would have been difficult to address at home: "*Severe fungating ulcerous areas on sacrum, buttocks, groin and thighs. Pain and desirability of support for family who included children. It was very difficult to dress severe wounds at home, patient was nursed on a clinitron (?) bed in (hospice) which was ideal for pain control and management of wounds* (DN)". Carer notes it was "*Our choice and need for pain control*". Case 335 did

have HAH support prior to admission but this apparently was not able to prevent the admission. In these cases admission apparently happened in spite of home support (206, 263, 335), or because the discrepancy between care need and the help which could be mobilised appeared too great to bridge (384, 454).

Five cases show similar balancing between patient problems and carer problems (315, 382, 407, 428, 443), but it is less clear that added home support would have been of no benefit. For 315 the district nurse cites "*Deterioration (rapid) of health. Husband unable to cope. Don't think the husband of this lady would have been able to cope with her at home*". The carer adds "*I was unable to meet my wife's great needs at home, although I wish I could have*". It is of some concern that we do not know what professional home support there was available to the carer, on what basis he was "unable to cope". However, although the carer would have liked the patient to be at home, he apparently does not consider it an option. For case 382 admission was due to "*Symptom control, confusional state* (DN)", "*Difficulty with sedation/ analgesia at home* (GP)" and "*because of her condition and the care she needed* (CR)". Against this the district nurse notes that "*the family (was) tired*". However, there is no indication of level of home support, and whether the tiredness of the family could have been prevented. The information for case 407 is also unclear. The district nurse states: "*Pain control, relatives could not cope, bad situation at home, patient also had problems with bad arthritis*". The carer states "*Looking after her in a private home had ceased to be a viable option*". We do not know why relatives were unable to cope, and why there was a "bad situation" and home care no longer viable. The patient was, however, "*in a private nursing home ... for the last five months of her life* (CR)", and referral to HAH occurred nearly ten months before death (with a brief episode of care at that point). Thus care needs over a long period, with possibly poor informal backup, may have made institutional care more appropriate. For case 428 the district nurse states "*unable to weight bear, extensive varicose leg ulcers*" and the GP "*Fell and fractured a rib, loss of mobility, lived alone*". These explanations in themselves do not mean that home death was impossible, although a lot of input would be required. There is no information about home support. For 443 breathlessness was the problem: "*Severe breathing problems* (DN)"; "*.. breathlessness was so distressing and hard to relieve that it was difficult for the family to be responsible for caring for him. He and they were on tenterhooks that he would stop breathing and in my opinion the hospice provided a release for the family so that they could be with him without feeling they*

had to DO something for him (GP)". On this basis "*Patient and family (were) satisfied that the hospice was the right place for him to die. We discussed this before he was admitted* (DN)". It is possible that 24 hour HAH care could have met these needs. However, HAH was not involved

Case 227 shows an element of preference for inpatient care, but perhaps in the face of care difficulties: "*Decision made by elderly husband and GP. Patient not easily managed at home, acute restlessness, totally immobile, difficulties in administering oral medicine and food and fluid intake*". The GP only cites "*uncontrolled diabetes*", while the carer does not comment, but notes that the care in hospital was "*deplorably bad*". HAH was provided prior to admission, thus added home care is unlikely to have helped.

For two cases (277, 329) there was a clear preference for inpatient care which is unlikely to have been changed through professional support. For 277 the district nurse and GP explain "*This lady wanted to die in hospital* (DN)"; "*Patient's wishes. Husband's emotional difficulties. Died in (private) hospital* (GP)". For 329 "*Symptom control - not tolerating oral intake. Given i.v. fluid* (GP)", could probably have been managed at home. However, the key reasons for inpatient care appear to be "*1: That's what the patient wanted. 2: Young children at home, husband and patient decided she wanted to be in hospice* (DN)". There was a considerable amount of informal support at home.

In two cases family dynamics may have been more important than patient problems in causing inpatient admission. While issues of symptom control and assessment (DN, GP, CR) may have been managed at home for case 252, there was also "*stress within the home ... Due to the highly emotional state of both (carer and patient) it was difficult for both GPs and DNs to manage his care* (DN)" and "*(The hospice) certainly helped the family and supported what was a very difficult family and marriage dynamic* (GP)". While symptom control (DN, GP) and increasing disability from MS (GP) were important factors in the inpatient admission of case 326, the emphasis was on "*family social problems* (DN)"and "*domestic difficulties* (GP)". The carer notes how years of caring for a patient may leave the caregiver unable to cope with the emotional strain in the final stages, resulting in "*giving up*", isolation and guilt, and advocates

better understanding of the carer's situation. Longer term support for the carer may have helped, although the family and care situation was difficult.

Finally 241 is a case in which the carer indirectly indicates that she may not have been in a fit state to contemplate home care. The district nurse merely attributes admission to "*breathing problems*" and the carer "*his heart*". However, the carer apologises for responding to the questionnaire so late as she "*also lost my mother 11 weeks before my father*". We cannot know if added home support would have helped, but care at home may have represented a greater strain on the carer than normal.

In summary, for most of these sixteen cases it appears unlikely that added home care could have played a role in enabling the patient to die at home. However, due to lack of information, some doubts remain whether six patients may have derived some benefit from home care or not (241, 315, 382, 407, 428, 443), although it may have had little relevance in relation to their place of death. Nevertheless, the respondents did not seem to consider care at home as an option.

- Emphasis on informal care support in explanations of inpatient deaths

There were twelve cases in this category (Table 5.8). For seven of these a preference for inpatient care was mentioned (195, 232, 258, 309, 377, 378, 447), although we have to consider what the basis for this preference was. Furthermore, anxiety over death at home was noted (201, 358, 388), and there was also some mention of family conflict (360, 378) and unsuitable home conditions (309). Home nursing support may therefore not have been wanted or may not have been able to address the problems of these cases.

Table 5.8: Emphasis on carer problems in explanations of inpatient deaths; (c) control

	DN	GP	CARER
195	Pref	Cutc	Ctired
201	Cutc, Ctired, Clin, Ppsych	Cutc, Cpsych	Cond
213	"No DN contact"	Cpract, Cutc	
232	Pref, Cpract		-
258 (c)	Cpsych, Misc		Pref, Ctired?
309	Pref	Chome, Cutc	Pref, Chome
360	Cfam	Cfam	Cfam
377	Cutc, Cpract	Pref, Care need?	Cutc, Clin
378 (c)	Clin, Pref, Cfam	Cfam	
388	Cpsych, Misc	Clin, Cpsych	
391	Cpract	Cpract	
447	Pref, Cutc, Cpract	Clin, Pref, Cpsych, Cutc	Clin

KEY: **Care need**: patient physical care needs; **Cfam**: family dynamics; **Chome**: unsuitable home situation; **Clin**: clinical event or procedure; **Cond**: patient condition; **Cpract**: carer practical – lack of informal support; **Ctired**: carer tiredness: **Cutc**: carer unable to cope; **Misc**: miscellaneous; **Ppsych**: Patient psychological problems; **Pref**: preference; **Supp**: problems with professional support; - : not possible to code (e.g. "don't know")

Two cases showed clear preference for inpatient care (309, 447). For 309 both the district nurse's response: "*Family and patient requested*", and carer's response: "*It was inappropriate for (the patient) to die at home with her son present*", show a preference for inpatient care. The GP notes that "*Husband and son - aged 11 years - (were) finding it very difficult to cope*". This patient had had HAH for four nights prior to admission but preference was nevertheless for inpatient care. For 447 there was some difficulty in controlling symptoms (GP). Nevertheless, there was a clear patient preference for hospice care: "*.. she had previously requested (hospice care) as she did not want her husband to have to nurse her at home as she had nursed her own mother until she died* (DN)"; "*Had clearly stated from the outset that she did not want terminal phase/ death at home (GP)*".

In two cases health professionals felt that care at home was possible, but the carers opted for inpatient care (195, 388). For 195 the district nurse felt the patient would have been "*suitable for terminal care at home*" and felt they were able to "*provide such a high level of support before admission*". Nevertheless, the family preferred hospice care when a bed became available (DN). The GP states "*wife unable to cope*" while the carer writes "*Mostly to give me a rest but died within 48 hours peacefully*". For 388 the GP notes "*the patient was no problem to care for at home*" when the patient deteriorated. However, carer anxiety and refusal of care prevented home death: "*Wife was afraid to be alone with husband. Felt safe at (hospice). All*

possible help was offered to the (carer), was often declined (DN)"; "*Wife frightened and not really coping anyway* (GP)". Although home death appears to have been possible in these cases, it is unlikely to have been appropriate.

For two more cases (232, 377) preference for inpatient care was claimed. However, this preference may have emerged from a prolonged period of caring at home. For 232 the district nurse states inpatient death was "*Patient and carer's wish. Elderly couple with no relatives*", while the carer, who did not complete the questionnaire, commented in a letter that she had nursed the patient with the help of neighbours and community nurses for a long period. She notes that the care in hospice (last four days) was good. For 377 the district nurse states: "*Family unable to cope - elderly*", and the GP writes: "*Relatives' wish. Very weak*". The carer's response may again suggests care over a longer period: "*Both of us were unable to cope anymore at home and also my husband needed more medical care to help him cope with his illness than I was able to give him ...* ". For 377 records show input of HAH for one night only prior to admission. It is difficult to assess whether more support at an early stage may have helped. However, we should note that the carer in both cases was elderly.

Anxiety appears to be a key reason for inpatient death in case 201 and 258. For 201 both the district nurse and GP comment: "*Inability of the carer to cope with the patient's distress and symptoms.*. (DN)"; "*Wife unable to cope due to own anxiety/ depression, chronic problem ... HAH initiated but patient required 2 x urgent admissions to (hospice). Was one of few patients who would have been better cared for in hospice for final weeks due to wife's mental state* (GP)". For case 258 the district nurse attributes the inpatient death to the carer's "*fear of husband dying at home*", but also to "*... wife's reluctance to have extra help offered*". The GP states that "*(the patient's) wife had coped with terminal illness with husband at home. When he became so ill 1/7 before dying she-I felt admission then was right to hospital*". Accounts suggest that in neither case was availability of additional home support likely to have changed the course of events.

For two patients (360, 378) family dynamics clearly prevented home death, and it appears that added support would not have helped. One of these, case 360, did have HAH support. For case 360 responses are

as follows: "*Complex family problems* (DN)"; "*Poor home circumstances* (GP)"; "*Nursing care being stopped because of difficulty at home, (home caregivers and family) causing trouble and distress to my mother and nurses* (CR)". For 378 the district nurse reports that following deterioration "*Patient and family wished admission .. Patient felt secure away from personal problems at home* (DN)", and the GP adds "*Poor marital relationship. Husband did not want to care for her at home. (The patient) only felt comfortable and in less pain when she was admitted to (hospice). She was admitted frequently over the course of her illness over a number of years. I don't know how she would have coped otherwise* (GP)"

For case 213 and 391 it is difficult to judge whether added home support could have improved the situation. Case 213 was never referred to the district nursing team by the GP according to the district nurse. The GP only states that "*Patient lived alone. Family would have been unable to look after her/ cope with her death at home*". Apparently the home care option was not tried, and we know nothing of the patient state or preference, nor carer views. For 391 there was a lack of informal support: "*No carer support* (DN)"; "*Family - 4 children - living considerable distance away. As wife recently died family could have no more leave from work*". Nevertheless, this in itself should not make it impossible to manage this patient at home, particularly as the patient initially "*was reluctant to go into hospice* (GP)". There was no information about professional home support.

In summary, in most of these cases continued care at home appeared inappropriate. For 232 and 377 it is possible that preference for inpatient care could have stemmed from lack of support, but the age of the carers may suggest inpatient care was more appropriate. For case 213 and 391 it was difficult to assess, but the fact that the patient lived alone would make care at home more difficult.

5.5 CHAPTER 5 SUMMARY AND DISCUSSION

5.5.1 Summary of results

Content analysis of respondents' accounts of inpatient deaths suggests that for the majority of RCT patients who died as inpatients, home death may not have been appropriate, and place of death that was attributed solely to reasons other than home care (5.4.7.3). The reported course of events, distressful nature of the illness, level and complexity of patient care needs, the length of time over which care was required, family conflict, carer psychological problems, unsuitability of home setting or patient and carer's own preference, suggested that inpatient care may have been the more suitable option. However, we noted that specialist support may have been able to address some of the problems relating to preparing and supporting relatives, dealing with complex symptom control needs and tackling patient and carer anxiety and depression.

Nevertheless, according to respondents' accounts there were 21 (27%) of 77 patients who would have benefited from additional home care (section 5.4.7.1) and for whom inpatient death was attributed to lack of such support. However, this does not allow us to conclude that added home support would have changed place of death. In ten of these cases there was reportedly a need for 24 hour care (in three cases equated with HAH care), in five cases a need for night nursing or sitting, in seven cases a need for help in general, and in one case a need for HAH in particular. In four cases there was an indication that it was not the help per se, but rather the speed at which it could be mobilised which was the issue. The length of the period for which care was required or problems in introducing support may have complicated the situation in two cases.

According to respondents there were furthermore 7 (9%) cases who probably would have benefited from additional home care, although deficiencies in home care were apparently not perceived to have directly affected place of death (section 5.4.7.2). Need for more Macmillan support, expert medical advice, social care and domestic support were mentioned in these cases. However, for two cases the problem may have

been resistance to support, and for two cases the key issue appeared to be that care should have started much earlier to help prevent carer exhaustion.

Thus the content analysis of accounts suggests that for up to one third of the RCT patients who died as inpatients, added home nursing support may have improved care conditions. Respondents furthermore attributed death in inpatient care to insufficient support in many of these cases, although we have no means of assessing the validity of these assumptions. The additional support reportedly required mainly took the form of 24 hour care, night care or general nursing care, i.e. the type of care provided by HAH, Marie Curie and other community nursing services. There was little call for more specialist care. However, respondents may think along familiar lines when considering the need for professional support, i.e. in terms of the community nursing services they regularly use. While there may be a possible role for more specialist support in the home for preparing relatives for death, dealing with complex symptoms and alleviating patient and carer anxiety and depression, respondents may think of inpatient specialist care solutions for such problems, and not consider whether such specialist support may also improve home care. There are three community Macmillan nurses in the area, and specialists in palliative medicine at the local hospice may also do home visits, but there is little coordinated specialist input in the community. Nevertheless, according to respondent accounts the main gap in provision appeared to lie in the hours of experienced nursing support available.

While accounts suggest that the majority of inpatient deaths in the RCT sample were unrelated to deficiencies in home support, it appears a notable minority were still perceived to lack adequate home care. For some of these patients inability to access sufficient care may have been due to the trial. Eight of 21 patients for whom inpatient death was attributed to lack of home support were controls, and three of seven patients for whom lack of home support was mentioned, but not perceived to precipitate inpatient admission. Thus inability to access HAH type support may have had a negative impact on the home care of these patients. This may indirectly imply that HAH could have made a difference to patient's situation in these cases, although its relation to death at home remains uncertain. In the remaining cases it is not always clear what prevented patients from accessing adequate care. For nine patients there was only mention of

inability to get care (198, 282, 286, 291,339, 343, 366, 351, 420). For others home care could reportedly not be mobilised quickly enough for discharge (239, 376), was hindered by geographical distance and health authority borders (274, 376), reluctance to accept added help (238, 400), GP's decision (306) or the issue may rather have been that care should have been introduced earlier in patient's illness (215, 318). Thus for patients who appear to be in a good position to die at home, there may still be difficulties in introducing support to those who need it and in timing the introduction of care appropriately.

5.5.2 Validity of the data

The content analysis relied on district nurses', GPs' and informal carers' accounts of the reasons for endstage inpatient admissions. This approach has several problems. The data were retrospective assessments subject to memory limitations and personal interpretation. The respondent may be a poor judge of the situation, the respondent's memory of events may change over time, and personal motives may bias the assessment. For instance, having one's patient randomised to the control condition may provide an incentive to report that the patient's care suffered as a result. Furthermore, responses required at the end of a questionnaire may not be given much time and thought, particularly by busy health professionals. Finally, asking someone to provide a single reason, or limited number of reasons, for an outcome which may stem from an interplay of multiple factors, necessarily invites selective interpretation. We are therefore dependent on what respondents chose to mention and not to mention.

One means of assessing whether explanations were generated in a random fashion or appeared to relate to an underlying reality, was to consider whether accounts for each case appeared consistent with each other. On the whole our analysis suggested there was internal consistency in the explanations provided for each case. Overall explanations which we expected to occur together did do so, while those which would have appeared contradictory did not. In particular, the scenarios in which deficiencies in home support were mentioned appeared different from those in which such deficiencies were not mentioned. When inpatient death was attributed to lack of home support (4.8.1), this problem was largely mentioned together with factors which appeared to have been caused by lack of home support or factors amenable to added home

support. The benefits of added home support appeared quite clear in these scenarios. When lack of home support was mentioned but not perceived to be a reason for inpatient death (4.8.2), patients may have benefited from home support, but the situations appeared more complex overall. Rarely in any of these cases (4.8.1 and 4.8.2) was there mention of family conflicts, unsuitable home conditions, preference for inpatient care or carers' fear of death at home, which may have made care at home very difficult or inappropriate. The vast majority of the scenarios in which deficiencies in home support were not mentioned, correspondingly suggest that additional home support may have been of little benefit. The scenarios which focused only on patient problems appeared to be such that both the professional and informal support available would be of little relevance (4.8.3, part 1), mainly due to the particular course of events. Thus it would be consistent with the situation that professional home support was not mentioned. The remaining scenarios under 4.8.3 were often those in which care at home probably would have been inappropriate, due to carer anxiety, preference, family conflict, unsuitable home conditions, extent of patient problems and /or lack of informal resources. There were a few instances, however, in which it was unclear whether added home support may have been of help.

It would seem plausible that GPs and district nurses would ensure they highlighted any problems with professional home support if they occurred, as they would be concerned about the level of care provision. Informal carers on the other hand may be less likely to criticise services. However, the covering letter of the questionnaire explained that the researchers were interested in "*how good the support for (the patient) was in the last two weeks of life, and also how good the support was for (the carer)*" which would hopefully have led carers to report any shortfalls in professional support. However, one would be concerned that respondents may also report lack of home support when it was not relevant or useful as a means of bolstering the argument for more funding for home care services. The apparent consistency of explanations may suggest this is not the case, however.

A further problem with the content analysis is that we are considering inpatient deaths without comparison with home deaths. Therefore, if inpatient death for instance is attributed to poor home support, we do not know whether there were similar patients with similarly poor home support who nevertheless died at home.

Nevertheless, unless a respondent is aiming to mislead, the content analysis should tell us whether professional home care was perceived to be of importance in each case, whether it featured as an issue, even if we do not know if it made a difference between home and inpatient death.

This content analysis was quite limited. The text material was very scant, there was only one fixed question to be answered with limited space for response, and there was no scope for clarifying respondents' replies. Furthermore, data collection formed part of a larger evaluation and was complete when analysis began. There was therefore no scope for further exploration of issues related to inpatient deaths through additional questions or broadening of the respondent sample. As noted, the present analysis of inpatient deaths relates to a highly selective sample of patients optimally placed to die at home. For a better understanding of the role attributed to home care deficiencies in endstage inpatient admissions we may ideally have wished to extend our data collection to a broader range of patients who died in inpatient care.

5.5.3 Issues for future research

The content analysis was useful as a supplement to the quantitative research, in that it provided some insight into factors precipitating endstage inpatient admissions for individual cases and the potential role of home care. However, it could only begin to indicate some of the complexity of the situations surrounding inpatient admission. More in-depth, preferably qualitative, research would be required to gain a better understanding of the factors and processes involved.

Professional support is probably one important factor to consider within this context. A challenge in home care provision may not only be to ensure that there are enough staff and resources available, but to ensure that the support reaches the patients who need it. The observational study raised the question of how disadvantaged patient groups can be identified for referral to palliative home care, e.g. older patients, patients of low socioeconomic background, those who have little access to services generally. The content analysis suggests there may also be a need to consider more closely the problems in introducing support to patients where and when required, once they have been identified as being in need of care.

The content analysis furthermore suggests the need to investigate more closely the types of problems involved in caring for the terminally ill at home, and the types of home care most appropriate for addressing these. This analysis began to illuminate the range of problems encountered. In particular it suggested a need to consider which types of problems are amenable to the type of palliative nursing offered by Marie Curie and HAH nursing care, and which types may require specialist support. Better insight into the clinical, practical, psychological and sociological problems associated with palliative home care will enable us to better assess which types and combinations of home support are most likely to prove effective in tackling problems of home care in the future. Other issues for investigation include whether patients and carers are best supported at home through longer term, lower intensity care input rather than through high intensity input of short duration.

Overall there is a need to improve our understanding of the complexity of factors surrounding death at home or in inpatient care, the types of problems represented, the forms of home care which may be relevant to address those problems, and the factors surrounding introduction of support into the home. A better understanding of these issues would enable future interventions and trials to be targeted more effectively.

CHAPTER 6: THESIS SUMMARY AND DISCUSSION

6.1 INTRODUCTION

Our review of factors associated with home death in Chapter 1, suggested that added palliative home care support was likely to increase the number of patients dying at home. It was argued that the negative association found between home death and lack of informal support, old age, being female and having low socioeconomic status largely could be attributed to lack of care resources in the home. Furthermore, to the extent that clinical variables are linked to caregiver burden and symptom control needs, their negative impact on home death should be mitigated by increased professional support. In support of this several studies showed that patients who received palliative home care were indeed more likely to die at home than those who did not.

The problem facing us, however, was that the characteristics of these home care patients often were the same as those of patients who died at home. Poor informal support, old age, low socioeconomic status, high care dependency, CNS tumours and haematological malignancy appeared to prevent both home care referral and home death. The apparently beneficial effects of home care may therefore be attributable to case mix. Alternatively, certain patient groups may be better able to die at home at least partly because of their better access to home care. Previous research has not resolved this issue satisfactorily. This thesis aimed to assess the impact of a local hospice at home service (HAH) on home death. A number of approaches were utilised to address the research question; an observational study, a randomised controlled trial, and quantitative and qualitative post hoc analyses of the RCT data.

In this chapter Section 6.2 gives a brief summary of the thesis research findings. Section 6.3 considers why we failed to find evidence that HAH care led to an increase in home death. Two main explanations are discussed. The first is that the service did not have an impact on place of death. We suggest how changes to the service, its target group, referral pattern or setting may have increased the proportion of home deaths. The second explanation is that HAH did have an impact on place of death, but it was not possible to

demonstrate this using the adopted study approach. We consider how the research approach may have been changed to increase likelihood of detecting an effect of HAH. Section 6. 4 asks whether place of death was the appropriate choice for an outcome measure. Section 6.5 considers some of the lessons learned from the studies within this thesis and the implications for policy and future research. A section of key messages for policy and research within this area ends the chapter.

6.2 HAH AND HOME DEATH: SUMMARY OF FINDINGS

- Observational study

In the observational study multivariate logistic regression was used to investigate the relationship between HAH and home death and to control for potential confounders, as identified through univariate analysis. A significant relationship between HAH and home death was found. In particular, patients who were admitted to HAH late (<=7 days before death) were considerably more likely to die at home compared to patients who had never been referred (OR 494.2, CI 25.0-9756.1). A considerably smaller but significant relationship was found between early onset of HAH care and home death (OR 7.2, CI 1.6-32.4). However, patients who were merely referred to HAH were also more likely to die at home than those who had never been referred (OR 4.1, CI 1.7-10.0) and early start of HAH care did not differ significantly from mere referral in its contribution to home death in the model.

Thus when controlling for potentially confounding variables through multivariate logistic regression, a strong association between HAH and home death was found, particularly for late onset of HAH care. However, two concerns led us to question whether this implied a causal relationship between HAH and home death. First, the finding that mere referral to HAH, with no input, was positively associated with home death, suggested there were elements of case mix for which we had failed to control. These elements of case mix may well account for the relationship between early HAH onset and home death and may also to a large extent account for the association between late HAH onset and home death. Second, the strongest association between HAH and home death was found for care which began in the last week of

life. This necessarily means that the patients involved were at home at least part of their last week of life. This led us to ask whether patients who were able to remain at home until death had late onset of HAH care, rather than HAH enabling these patients to die at home. Other home care services were also positively associated with home death, but concerns about case mix remained.

The univariate analysis furthermore confirmed that patients who were referred to HAH were considerably different from patients not referred to HAH. They were more likely to have characteristics and additional service support which could plausibly be linked to increased likelihood of home death. Thus patients referred to HAH were likely to be better placed to die at home than most terminally ill patients.

- Randomised controlled trial

The observational study clearly showed that there was a relationship between HAH and home death worthy of further investigation, but doubts remained about HAH as a causal factor in this relationship. To establish whether HAH actually had an impact on home death a randomised controlled trial (RCT) was conducted with patients referred to HAH as the study sample. The analysis was intention to treat.

Analysis of patient groups showed that there were no significant differences between the control and intervention group on the variables measured, apart from the intervention itself. In the HAH group 67% of patients died at home compared to 58% in the control group. This difference was not statistically significant. Thus the observed difference may be attributed to chance, and we could not conclude that HAH had an impact on home death.

- Actual treatment analysis

Two concerns from the RCT led us to explore the relationship between HAH and home death further through multivariate logistic regression. There was considerable loss of statistical power in the trial, although results suggest that even with the planned power to detect a difference of 15%, we may not have

observed a significant relationship. There was furthermore considerable dilution of the treatment effect. Only 61% of patients allocated to HAH obtained the service, making it less likely that one would observe an effect of the service in an intention to treat analysis.

The logistic regression analysis showed a significant association between late onset of HAH care (<=12 days before death) and home death (OR 5.3. CI 1.8-15.3). There was no significant relationship between early onset of HAH care and home death. This result raises doubts over a causal relationship between HAH and home death for two reasons. First, there was a large reduction in the association between HAH and home death between the observational study and the RCT study. The observational study sample represented the whole range of the cancer population, the RCT considered patients referred to HAH only. Thus case mix differences between those who did and did not receive HAH care were reduced between studies, and the odds ratio for home death under HAH care was similarly reduced. This supports the earlier conclusion that the association between HAH and home death in the observational study was largely due to case mix. We should, however, note that the difference in home deaths among RCT patients admitted and not admitted to HAH (78% and 53% respectively) was smaller than that between referred patients admitted and not admitted to HAH in the observational study (86% and 44% respectively). Thus it is possible that the relationship between HAH and home death may have changed between studies, which in part could account for the difference in results. However, changes in percentages were small and may be due to random variation.

The second concern is that the association which remained between HAH and home death in the RCT logistic regression was for late onset of care only. Thus we may only be observing that patients who were able to remain at home towards the end of life were more likely to have a late onset of HAH care, not that HAH enabled patients to remain at home. This is in effect another explanation based on case mix as patients who were able to be at home towards the end of life are likely to have a specific set of characteristics and circumstances conducive to home death.

The positive association between other home care (Marie Curie and night nursing) and home death was of the same magnitude in the RCT sample and observational study, and did not depend on the timing of the onset of care. Thus this association appears more "robust" in the face of changes in case mix diversity. Furthermore, it cannot as easily be assumed that results simply reflect that patients who were able to be at home close to death received the service. Nevertheless, we cannot rule out the possibility that case mix differences account for some of the association between other home care and home death.

Overall there was no clear evidence that HAH increased the percentage of home deaths. To the extent that it had an effect, its contribution appeared no greater, perhaps smaller, than that of other, less intensive home care services. The question was raised whether introduction of added home care may have little or no further impact when introduced on top of good existing care provision among patients already well placed to die at home. The high percentage of home deaths even within the control group attests to the unusual characteristics of the sample. There may be a level beyond which further increase in home death cannot be realistically achieved by increases in level of home nursing services.

- Content analysis

The content analysis investigated whether RCT patients who died in inpatient care may represent cases for which added home care would have had little or no further impact . These were patients who probably belonged to a privileged group where home death was concerned, yet failed to die at home. These patients may therefore have represented the problems which are beyond the scope of added home care, or at least the type of home care available within the study area.

This question required a focus on each individual case. The quantitative analysis performed at an aggregate level had allowed us to test hypotheses and replicate findings emerging from past research, test whether there was an association between HAH, other home care and home death, and quantify the size of any such association. In theory at least, it also enabled us to investigate causation through the RCT. However, by considering the level of the individual, the content analysis enabled us to gain insight into the actual

problems associated with caring for each patient at home and to assess to what extent added home support may have benefited a given individual or not, according to those caring for the patient.

The content analysis suggested that for many RCT patients who died as inpatients death at home may have been inappropriate due to the level and complexity of care needs, the particular course of events, the length of time over which care was required, family conflict, unsuitability of the home setting, carer psychological problems and preference for inpatient care.

Nevertheless, according to those responsible for the patient's home care, up to one third of the RCT sample who died in inpatient care may have benefited from more home support. For many of these patients insufficient professional home support was perceived to be an important factor in precipitating death in inpatient care. The data do not permit us to conclude that added home care would have changed place of death in these cases, only that there were perceived gaps in care provision. Consistency in the reasons provided for each case suggested that respondents did not attribute inpatient death to insufficient home care at random, but that lack of home care was only mentioned where patients' problems could be addressed by such care. Nevertheless, the data were limited in scope and our interpretation is wholly dependent on the subjective assessments of the respondents.

According to respondent accounts, the professional support which was lacking was the type of home care provided by HAH, Marie Curie nursing and other community nursing services. Some of these patients may have been prevented from accessing more home care because they were controls. The question was raised whether inability to get additional home care for the remaining patients may reflect problems in distribution and introduction of care rather than the level of available care. There was little mention of need for specialist support. However, the analysis discussion noted that this may have been beneficial in some situations. Furthermore, it may be difficult for non-specialists and families to assess to what extent specialist palliative support may help in ameliorating complex patient problems.

The content analysis began to show us the complexity of each individual case. It showed that while there were cases for which lack of professional home support was perceived to precipitate inpatient death, there were also a range of situations in which level of home support was not reported as an issue. We may need to understand the complexity of these situations better in order to target home care appropriately whether in the form of volunteer, experienced nursing or specialist support.

- Summary conclusion

In summary the present evidence does not present a convincing case that HAH increased the number of home deaths within the study sample. The RCT intention to treat analysis showed no significant difference between intervention and control group, and any observed relationship between HAH and home death in the logistic regression analyses may be due to case mix differences. To the extent that HAH made a contribution, it appeared to be no greater than that of other, less intensive home care services. The content analysis suggests there was a perceived lack of home support for some of the RCT patients who died in inpatient care. However, it is not possible to assess whether added home support would have changed place of death in these cases.

In the next section we consider further why we failed to find convincing evidence that HAH had an impact on home deaths. This may be because the HAH had no impact or because of the research methods used. We consider potential solutions to the problems in each instance.

6.3 REASONS FOR OBSERVED LACK OF IMPACT OF HAH ON HOME DEATH

6.3.1 The HAH service had no impact on home death

If HAH did not have an impact on place of death, why did it not do so? HAH input represented a considerable amount of experienced palliative nursing care. The randomised controlled trial showed that HAH had a significant, positive impact on symptom control and adequacy of care, as assessed by the

informal carer, district nurse and GP (Grande et al, 2000). That it did so in spite of the difficulties of the trial, including loss of power and dilution of the treatment effect, suggests that the service did make a considerable difference to home care. However, the perceived improvement in symptom control and care was not what was required to change place of death for this patient sample. There may be several possible reasons why HAH did not have an impact on place of death, in spite of apparently improving home care. Two of these, patient characteristics and level of other resources we have briefly mentioned earlier.

- The characteristics of the patients referred to HAH

The specific characteristics and situation of patients referred to HAH may have ensured that they as a group were likely to die at home anyway. Fifty three percent of RCT patients who had no HAH input died at home. This is far higher than for cancer patients not referred to HAH (23%) or the overall percentage of cancer home deaths in East Anglia (29%, Higginson et al, 1999). There may be something about the resources available to these patients, their disease progression or the patients' and families' attitudes towards terminal disease which made home death possible. Chapter 2 showed that patients referred to HAH displayed the characteristics (e.g. age, socioeconomic status) which are normally associated with death at home. Although these variables were not found to be directly associated with place of death in this case, they may signal underlying patterns which confer an advantage. Referral to HAH implies a preference for care at home both on the part of the patient and the informal carer. Preference for home care is associated with death at home (Karlsen and Addington Hall, 1998, McWhinney et al 1994). Referral furthermore implies that the patient's district nurse and GP assess the home situation to be appropriate for home care and that they willingly take responsibility for the patient's care at home. In this situation HAH input may often make home care easier, but its absence may not change the determination of the involved parties to attempt to achieve a home death.

- Level of other home support provision

Professional home care may make a considerable difference in achieving death at home. However, HAH patients may already have had a sufficiently high level of care that HAH did not make any further impact on place of death. Patients referred to HAH patients were more likely to have other forms of home care (and hospice) services compared to other patients, and those admitted to the service had more home care input than those referred but not admitted. HAH may only have provided the "icing on the cake" for those who already had a lot of care, without altering the outcome. Logistic regression analysis showed existing home care services were significantly associated with home death independently of HAH. Post hoc analysis of RCT data showed the contribution of Marie Curie and night nursing to the logistic regression model to be at least as large as that of HAH. Introduction of HAH on top of these services may have made little further contribution to the outcome. Although qualitative analysis of RCT patients who died in inpatient care suggests that some of these patients could have benefited from added home care, this may not have affected place of death

- Health professionals' use of the service

The way the service was perceived and used by health professionals may have ensured that only patients who were about to die at home anyway were referred to the service. The service was used almost exclusively as a terminal care service. The operational policy limit on care was two weeks, although in practice the service attempted to be more flexible. Health professionals would therefore aim to refer patients very close to death to ensure that the service remained with the patient until the end. When patients were that close to death, the factors determining place of death may well already be determined with little scope for HAH input to change matters. As was suggested by the logistic regression analysis, HAH would therefore be given to patients who were able to be at home at the end of life, rather than itself enabling patients to be at home towards the end of life.

The above explanations all relate to patterns of referral to HAH in that HAH patients were different from others in terms of general characteristics or context, amount of service input received or location in close proximity to death.

- The type of home care service provided

HAH may not have been the "right" type of service to achieve an increase in home deaths. Two possible issues may be that HAH needed to be more different from existing home care, or that its focus should have been more on discharge from secondary care.

Rather than complementing existing services, HAH served as an extension to the home care already in place. It was in effect an extended Marie Curie nursing service, indistinguishable from the latter except for the number of hours of care which could be provided and, possibly, a greater continuity of care due to a smaller team. Had HAH addressed different care needs and problems than Marie Curie, it may have had a greater impact. An alternative service may be a specialist team, similar to other home care teams in the UK, consisting e.g. of a physician, specialist nurses, social worker, physiotherapist, and providing advice and support rather than hands-on care. Such a team may address more complex problems (physical, psychological and social) and support existing community care. Furthermore it would not be constrained by the two week care limit imposed as part of HAH. Support could be introduced earlier and better planning and prevention of potential problems may result. As noted in Chapter 1 most evaluations of home care have been of this type of team, and have shown them to be associated with more deaths at home. However, case mix concerns will not allow us to conclude that such teams do increase the number of home deaths. The Cambridge area has three community Macmillan nurses, and physicians from the local hospice will do home visits, but there is no extensive, coordinated specialist home care provision in the area.

Consideration of HAH in the context of other hospital at home schemes may suggest it would have been successful in changing the balance from secondary to primary care had it focused on enabling discharge.

The service was designed both to prevent admission and enable discharge, but in practice 69% of referrals related to prevention of admission, i.e. the patient was at home when the referral was made.

A recent literature review by Shepperd (1999) provides evidence that hospital at home schemes reduce the number of hospital inpatient days (Donald et al, 1995, Rudd et al, 1997, Coast et al, 1998, Shepperd et al, 1998, Wilson et al, 1999), including one palliative care scheme (Hughes et al, 1992). All studies were RCTs, and all but one (Wilson et al, 1999) considered early discharge schemes. A range of conditions were represented: Donald et al (1995) and Coast et al (1998) considered elderly patients of all diagnoses, Wilson et al (1999) all patients with acute condition referred to their hospital at home scheme, Shepperd et al (1998) hip and knee replacement, hysterectomy and chronic obstructive airways disease patients, and Rudd et al (1997) medically stable stroke patients only. In contrast to the findings from these studies, there was no evidence that HAH had any impact on number of hospital inpatient days.

Enabling discharge and admission avoidance represent different situations. In the first instance a transfer in location of care is required, in the second, the patient only needs to be maintained in the same environment with (or without) added input. Discharge back into the home may present the greater challenge for which the family is more in need of help and support. It is therefore possible that HAH would have had greater impact on place of death if it had dedicated itself to enabling discharge. There were too few patients in our study to analyse the two situations separately. Unlike other hospital at home services reviewed, HAH was a supplement to existing community services, rather than serving as a replacement. This may also have made it less likely to bring about change.

The patient groups in the hospital at home services evaluated by Shepperd (1999) are likely to be different from palliative care patients in a number of ways. For one thing, discharge for these patients was mainly a matter of when rather than if, while for many terminal patients inpatient care may be the natural end point. Patient needs and the emotional impact on patient and family may also be considerably different. We need a better understanding of factors associated with discharge to assess whether results from general hospital at home services are transferable to a similar service directed at palliative care.

- Characteristics of the study area

There may be something unusual about the study area and not just patients referred to HAH. The observational study showed no impact of demographic or clinical variables on place of death, apart from diagnosis within a month of death and non-cancer causes of death. These relationships disappeared when service input was taken into account. Past research has quite consistently shown that variables such as age, sex and socioeconomic status have an impact on place of death. Thus the absence of any impact of these variables in the present study is somewhat at odds with previous findings. There are other data to suggest that the region is unusual. The percentage of cancer deaths at home in East Anglia is the highest in the UK (29%), and the correlation between percentage of home death and UPA (r=-0.23) and Townsend deprivation scores (r=-0.17) among the lowest in England (Higginson, 1999, maximum r=–0.62 and r= -0.57 respectively in North Thames). The study area may predominantly display the demographic patterns of a rural community, in which even the city of Cambridge is of relatively small size and provincial. Relationships between residents and the local primary care services are usually stable and sustained over time. Local research has suggested that there is high commitment towards palliative care among GPs and district nurses in the area. In a Cambridgeshire survey 81 (63%) of 128 GPs and 58 (83%) of 70 district nurses stated they would like to give more time to this patient group, and many of those who felt they gave adequate time stated this was because they made time for these patients (Grande, 1994). In contrast Cartwright et al's (1973) nationwide study found that 40% of GPs and 67% of district nurses would like to give more time, while Seale and Cartwright (1994) found this for 43% of GPs and 58% of district nurses. Perhaps more indicative of local attitude is that while 13 of 54 district nurses and 19 of 53 GPs felt that HAH had increased their workload, one half or more of these stated the increase was welcome given this particular patient group (Grande et al, 1998). The area may therefore be unusual in its stability and commitment to primary palliative care. This may mean additional palliative home care services have less impact on home death, although they may increase quality of care.

6.3.2 Potential ways of changing the percentage of home deaths

The above explanations suggest there are a number of changes which may increase the percentage of home deaths using a HAH type service. However, we may need a better understanding of factors causing inpatient deaths to really increase the number of deaths at home.

- Changing the patients referred

HAH may not have an impact because it fails to reach those who need it the most. It may at present only reach those best able to die at home, whether this is due to having the "right" personal, home or disease characteristics or to having enough professional home care already. Patient characteristics and service input are probably interrelated, as past research suggests that the people with the "right" characteristics for home death also are more likely to access home care. Whether it is only better service access per se which enables patients to die at home or a combination of patient characteristics and services, cannot be disentangled here. It does appear, however, that if HAH is going to make an impact on place of death, it must be introduced to patients who do not already have a lot of home support. Conversely, if resources tend to accumulate around a few patients, for whatever reason, a new service introduced indiscriminately may only exacerbate this trend and yield diminishing returns. Changing referral patterns may require making health professionals look beyond the high profile cancer patients and stop them referring only patients that are "safe bets" in relation to home death. This may mean that the service needs to offer more than a limited two weeks of terminal care.

- Changing the characteristics of the service

Home deaths may possibly be increased by enabling HAH to admit more of the patients referred. This may be achieved by making the service respond more rapidly, as early death is one of the factors which preclude admission, or by encouraging earlier referral. Rapid response would require more people on stand by, which would require more resources, or a less intensive input than 24 hour care. However, if HAH had no

impact on home death, as appears to be the case, increasing the rate of admission may not increase home deaths. Nevertheless, the qualitative analysis may suggest that quicker mobilisation of care would have helped in some cases.

If HAH input normally occurs so close to death that place of death is already determined, earlier referral allowing earlier introduction of the service may enable HAH to have an influence on the course of events. This would require the service to extend its care period limit beyond two weeks, possibly starting with a moderate amount of input and increasing it to 24 hour care as death approaches. This would probably require the service to be resourced at a considerably higher level that it is at present. One may ask if such a care model is not implemented already for many patients through the combination of initial home care from other services and a subsequent addition of HAH care. A closer consideration of what happens at present when services work in combination may provide some pointers.

If the focus of the HAH service was changed towards enabling inpatient discharge rather than "preventing admission", its impact may change. As noted, it is more difficult to enable home death from inpatient care than from home care. In the latter case all that is required is preservation of an existing situation. One would need to scrutinise patients who failed to be admitted to HAH from secondary care to assess whether there was any means of discharging them through added home support. The content analysis did suggest this may have been the case for some patients who died in inpatient care. Furthermore, one would need to assess whether there are more palliative care patients who could benefit from discharge, who at present fail to be referred to HAH. Shepperd (1999) notes that few patients in practice prove eligible for hospital at home early discharge, and one would need to assess whether HAH in its present form already enables discharge for all palliative patients who could benefit.

Finally, it was noted that a specialist palliative home care team may have had an impact on home deaths where HAH did not. A change towards specialist team care would, however, imply more than just changing the HAH service. It would mean discontinuing HAH and starting a new service, as the two types of home care are very different.

- Introducing HAH services in other areas

If HAH fails to have an impact because the study area is privileged in terms of its population and/or health care resources, this would suggest that a similar service introduced in another, more deprived context, may have greater impact on place of death. Local circumstances, including the organisation and prevalence of other services and local referral practices may influence the outcome (Thorne et al, 1994). Shepperd (1999) notes how the findings from evaluations of hospital at home services are very context dependent.

Targeting services towards more deprived areas may present inherent difficulties, however. Tudor Hart (1971) voiced the paradox of the inverse care law, that areas with populations most in need of health care support are those least likely to attract good service cover. It may be precisely Cambridge's affluence, education and positive attitude to palliative care which facilitated the establishment of a local hospice at home service, and which at the same time have led the service to have no apparent effect on death at home.

6.3.3 The research methods used failed to detect that HAH had an impact on home death

This section considers that HAH may in fact have had an impact on home death, albeit small, but that problems with the research methods meant we failed to detect this.

- Observational study and logistic regression analyses

The observational study methodology means we cannot be certain that our study groups did not differ in ways which influenced the outcome. A similar problem existed for the post hoc logistic regression analysis of the RCT sample. By using multivariate logistic regression we were able to grapple with multiple variables, and to show how both HAH and other factors were related to home death. However, it is inherent in this methodology that we can show association only. We are unable to say that a variable has caused the measured outcome, due to the inability to control for any unknown confounding variables.

Probably the best approximation to finding the actual effect of HAH using non-randomised methodology was in our logistic regression of the RCT sample patients, as we had eliminated much of the case mix difference between those who did and did not receive HAH, compared to the initial observational study. According to Britton et al (1998) the results of non-randomised studies are most likely to be similar to those of randomised studies when both use the same exclusion criteria and when potential prognostic factors are well understood and controlled for. However, while the post hoc logistic regression analysis and the RCT utilised a similar patient sample, we still cannot claim that confounding variables were well understood and controlled for. A further problem is that by using the RCT sample for analysis we not only achieved greater homogeneity, but probably the homogeneity of an "elite". Thus the external validity of the results may be questionable.

Nevertheless, an association remained between HAH and home death within this homogenous "elite", but only for patients who began their HAH care close to death. This we took to indicate that late HAH input was simply associated with patients who were able to be at home close to death anyway, not as an indication of any causal relationship. However, it may equally mean that HAH caused an increase in the odds of dying at home. The referral strategies adopted to accommodate HAH operational policy of a two week limit on terminal care, may have ensured it would always appear that HAH was associated with patients who would die at home anyway. Intensive HAH input close to death may be the circumstances under which HAH is most effective at securing home death. The methodology offered us no means of disentangling the two interpretations.

Only by comparing patient groups who are otherwise equal in all respects and giving HAH to only one, can we arrive at a conclusion. The RCT offers the means of tackling this problem, but only if the trial is successful.

- Randomised controlled trial

The RCT is able to show a relationship between a single, causal variable and its outcome (or slightly more than one causal variable in multifactorial designs). It is the only effective method in establishing a causal

relationship between HAH and home death. Without the earlier observational study, however, we would not know how selective the RCT sample was in relation to home death, and thus the threat to external validity posed.

The RCT failed to show a significant effect of HAH. However, this may not mean the service had no impact on home death but rather reflect problems of loss of power and dilution of the treatment effect. Failure to find a significant result may be associated with problems inherent in conducting RCTs in this field of research (Rinck et al, 1997, McWhinney et al, 1994, Grande and Todd, 2000). Evaluation of palliative nursing care may be pushing at the limits within which RCTs are feasible and useful (Black, 1996, McWhinney et al, 1994). It is inherent in RCT methodology that to make it effective, we need to achieve a degree of control over the intervention and the trial which is difficult to achieve in palliative care, or indeed in most evaluations of health services. Black (1996) notes how "the problems that RCTs encounter arise from a largely uncritical transfer of a well developed scientific method in pharmacological research to the evaluation of other health technologies and to health services". HAH is not a drug or a surgical intervention. It is not even a standardised procedure given as a remedy for a particular, defined problem. It furthermore operates within the real world with all its constraints.

A key problem in the trial was loss of statistical power. This was due to a need to ensure that vulnerable patients did not fail to receive available care, that funding was fully utilised and that professionals would cooperate. The trial furthermore had to be completed on time to inform funding. These issues related to evaluating a real life service operating in a political context.

Furthermore, there is not a stable, predicable course to terminal illness (Rinck et al, 1997). In the trial there was no means of predicting or controlling patients' changing circumstances, which in turn meant that many intervention patients failed to receive their allocated treatment. This lead to a dilution of the treatment effect. Problems in providing an accurate prognosis often lead patients to be referred too late in palliative care trials (McWhinney et al, 1994, Grande and Todd, 2000).

In the HAH trial we could not standardise the intervention, as palliative care needs to be adaptable to patients' circumstances. Neither could we control the format of standard care delivery as palliative care is inherently multidisciplinary, and again, flexible (Grande and Todd, 2000). At the same time there were necessarily many similarities between HAH and other nursing care, which made it difficult to define how the intervention differed from standard care. The same nurses may work for different services as well, which raises concerns of contamination between conditions. The heterogeneity of standard care and intervention would make it more difficult to show an effect statistically (McKee et al, 1999), while contamination and/or failure to distinguish between trial conditions may render RCTs untenable (Black, 1996, Rinck et al, 1997).

Finally, the defined desirable outcome, home death, may not have been the actual aim of the people involved. Although in theory a HAH referral means a preference for home care, we do not know that home death was necessarily the goal among all parties involved, nor for any party throughout the whole of the terminal care period. Hinton (1994a) found that preference for home death may decrease as death approaches. The qualitative analysis clearly suggests there were situations in which death at home was not considered desirable. The service, if providing good palliative care, would aim to accommodate the wishes of patient and family, not work blindly towards death at home if this was not desired.

- Content analysis of open ended questionnaire responses

The content analysis began to illuminate some of the complexity of the causes of place of death, but was necessarily very limited given the material to hand. One problem with this analysis was its reliance on retrospective assessment which would be subject to memory limitations and personal interpretation. Busy health professionals in particular may not have given much time and thought to their response. Furthermore, the respondent may have extraneous motives, e.g. wanting to emphasise the importance of home support, apportion blame, rationalise events, or coping with feelings of guilt. Even if the reasons given were a true reflection of the precipitating cause, it was not possible to establish the background factors which may have lead up to this cause.

Although the content analysis identified several cases in which lack of home care was perceived to contribute to inpatient death, this type of analysis does not enable us to tell whether HAH and other home support really would have prevented inpatient admission. The analysis itself alerted us to the fact that there usually was more than one aspect to consider. A further weakness of this analysis was that we could not compare patients who died in inpatient care with those who died at home, to establish whether the perceived factors associated with inpatient admission were indeed exclusive to the inpatient death sample. Thus while the content analysis indicated that for up to one third of patients who died in inpatient care there was insufficient home support, this analysis does not allow us to conclude that added home support would have led to home death for any of them.

6.3.4 Changing the research design

If we failed to find an impact of HAH due to the research approach rather than the service, how could the research approach have been changed to increase the likelihood of detecting an effect of HAH? Such changes would centre on the RCT, as the logistic regression analyses did show a relationship between HAH and home death, but not one which could be assumed to be causal. Some of the possible solutions would involve changing the service to suit the needs of the research. However, we may also need to know more about our research subject in order to target future studies better. This would require more in-depth qualitative approaches.

- Changes to the RCT design

Key among the problems of the RCT were loss of statistical power and dilution of the treatment effect. Loss of power stemmed from the unequal randomisation ratio of 4:1 and the limited time available for the study.

The study randomisation ratio was subject to political and ethical constraints. Randomisation was justified as a means of allocating limited resources. The 4:1 randomisation ratio was set because many of the patients allocated to hospital at home did not receive the service. Far more patients therefore had to be

allocated to hospital at home than to the control condition to ensure that the service ran at or near capacity. In addition 8% of suitable patients had to be excluded from the study to fill hospital at home spaces during quiet periods and accommodate emergency referrals. Although the value of the service had not been established, most health professionals would not perceive there to be equipoise between the intervention and control condition. It is perhaps natural in this situation to want terminally ill patients to have access to all care options available. It was therefore necessary to enable the service to reach as many patients as its resources permitted, thus ensuring the required cooperation from health professionals and addressing ethical concerns. Lack of such compromise would have led to the likely collapse of the trial.

The randomisation ratio could therefore only have been improved by increasing the rate of HAH admissions within the intervention group or by increasing the referral rate. Failure to admit to HAH was mainly due to the unpredictability and complexity of terminal illness. Had the service been able to respond more rapidly and flexibly, admissions could perhaps have been increased, but this would have required considerably more resources. An increase in referrals would have allowed the trial to shift the surplus of patients over to the control condition, and to this end encouragement was given to health professionals to refer. However, there is probably a limit to how much referrals could increase if such an increase meant a decreased likelihood of obtaining a HAH admission.

There are alternative randomisation designs which may be considered for RCTs. One alternative involves randomising the control group to a waiting list. Controls are then provided with the intervention at a later date. However, this solution is not feasible when patients have a limited life span, when any delay in the intervention may often be equivalent to receiving no intervention at all (McWhinney et al, 1994). Patient preference designs, whereby patients who express a preference receive their preferred treatment and the remainder are randomised, may be more ethical but are likely to further limit patient numbers and statistical power (Brewin and Bradley, 1989). The augmented home care offered by HAH was likely to be considered a desirable option by most patients who would like to remain at home. Although they may not have wanted the service immediately, the spectre of future deterioration would probably make patients reluctant to remove the possibility of future HAH care. The only patients likely to find HAH an unattractive or

indifferent option may be those who did not particularly wish to die at home. Thus a patient preference design in the case of HAH may have greatly reduced the number of patients randomised, and the ones to be randomised may be biased towards those who did not want to die at home. Cluster randomisation, e.g. by general practice (Addington Hall et al, 1992), may have offered the best alternative for a HAH trial. In this case randomisation is one step removed from the patient in that it has occurred before the patient was identified. While the intervention group may still be perceived as the more privileged group, access is now related to geographical location or surgery attachment, a situation more commonly experienced in everyday life (Grande and Todd, 2000). Providing HAH to a limited set of practices or geographical areas, with the intention to extend the coverage at a later date should the service prove successful, may have proved an acceptable solution. This would still have required careful thought given that HAH was a well advertised intervention provided within a relatively small geographical area. Furthermore, cluster randomised trials have less statistical power compared to similarly sized individually randomised trials, and therefore require an increase in sample size (Campbell and Grimshaw, 1998).

The limited time available for the study reflected the pragmatic constraints common to evaluations of health care interventions. The hospital at home service itself was only funded for a limited period, its future funding in part dependent on the outcome of the trial. The trial therefore needed to be completed and the results analysed in time to inform this process. Clearly if there had been unlimited funding available, issues of power could have been resolved. The RCT may be the best tool for establishing the impact of a treatment, but it requires adequate time and funding to be of use.

Changes in referrals to reflect a broader spectrum of the patient population may, as previously noted, have increased any effect of HAH, which in turn would have made it easier to detect within the trial. The estimate of treatment effect will necessarily be low if the patient selection procedures produce a study sample which little capacity to benefit from the intervention (Britton et al, 1998). As stated, a change in the patient sample may have required the service to be more flexible in its operational policy, specifically encourage referral of other patients than high profile cancer patients, and to remove its two week limit on terminal care, so that the client group would not be patients who were dying at home anyway.

Dilution of treatment effect was related to a failure to admit patients to the service. Enabling the service to admit more of the intervention group patients would not only have improved the randomisation ratio but also have reduced the dilution of the treatment effect. As noted this would probably have required more resources to allow the service to be more flexible and rapid response.

HAH augmented existing care and may not have been qualitatively different from other care offered. Hospital at home would be supplemented by general practitioner and district nurse input, and often also by other community care when less than 24 hour hospital at home input was provided. Standard care patients would often have care similar to that of HAH, e.g. Marie Curie nursing. This added to the problem of distinguishing between the intervention and control arm of the trial, thus making any effects more difficult to detect. Better standardisation of the intervention and restrictions on non-HAH care would have helped resolve this problem. However, such standardisation could not be achieved without placing artificial constraints on the situation. This would in turn mean that the results of the trial would lose external validity.

Each of these solutions involve changing the service itself and/or its referrals, or increasing the funding for the research. Changing the service would itself require more funding or impose restrictions which reduce external validity. An increase in cost will always be a contentious issue in research and service delivery.

One can argue that the strength of the trial was that it was run in a real setting, not under artificially controlled conditions, and that its difficulties, failure to admit patients key among them, were not purely methodological. They represent the type of environment in which a palliative home care service has to work. The RCT intention to treat analysis shows the real impact of HAH on its client group, where the service may fail to have an effect because it does not reach people in the first place, or because when it does, it does not substantially change the place of death. Failure to admit patients is an integral part of the HAH service picture. The intention to treat analysis may represent the best the service can do given the nature of palliative care and the service's resources, and demonstrates the impact of a service the real world rather than under ideal circumstances (Hollis and Campbell, 1999).

The question remains, however, about the appropriateness of using RCT methodology for palliative care research. McQuay and Moore (1994) argue that RCTs are "mandatory" for assessment of services and that palliative care should not be exempt just because it presents difficulties to research. Nevertheless they concede that some RCT designs may not be ethical in this context. Keeley (1999) on the other hand, commenting on the HAH trial (Grande et al, 1999), questions whether one can insist on RCTs of services which are of such "evident human desirability" that it would be difficult or unethical to withhold them. However, although interventions may seem desirable on the face of it, one cannot know their real impact until tested. For instance, it would perhaps appear "self evident" that a HAH service would lead to considerable increases in home deaths. In fact, our trial suggests that this is not necessarily so, given the present patient group and their resources. Nevertheless, the possibility that desirable treatment may be withheld from the terminally ill is not to be taken lightly, and one may question whether an RCT was ethical in the present case, given early signs that the trial would suffer from loss of power. However, the main reason that the trial suffered loss of power were the efforts to ensure that the research did not cause patients to lose out on care they could otherwise have had. Randomisation did not remove treatment, but served as a means of allocating it, each patient having an equal chance of care in a situation of limited resources. It was by no means clear how the resources could otherwise be fairly allocated, apart from doing so on an equally arbitrary first come, first served basis. Changing the data collection from prospective to retrospective furthermore meant that the RCT did not intrude on patients' lives or demand effort from them. Thus it was felt that continuing the trial was ethical as it would not have a negative impact on patient care and may yield valuable information. The actual patient numbers would still have given the trial 80% power to detect a difference in home death of 24%. While questions may remain regarding results on place of death, the trial did show that symptoms and adequacy of care were perceived to be better under the HAH than control condition (Grande et al, 2000).

The RCT remains our best means of establishing that an intervention has a measurable impact. Before choosing this approach, however, we need to be realistic about the challenges palliative care poses for research, and confident that the obstacles can be overcome and that the trial is likely to yield information of value. Any impact of the research on patients has to be ethically justified. There is no clear cut answer whether to employ RCT methodology in palliative care or not, each proposed trial has to be judged on its own merit. We may need

to gain considerable knowledge about the prognostic variables and the patient groups involved to conduct RCTs in palliative care successfully (see below). Ironically, the higher our degree of understanding about our subject area, the more likely we are also to be able to truly control for confounding variables in observational studies and therefore approximate the results of RCTs through non-randomised methodology (McKee et al, 1999).

- Use of qualitative methodology

As indicated above, we may not yet understand the issue sufficiently to adopt a quantitative research approach to factors affecting place of death. More qualitative research may be required (Brannen, 1992, Miller and Crabtree, 1992, Pope and Mays, 1995). Place of death is probably the outcome of a process of some complexity. The factors involved do not remain static. While the intervention itself will adapt to circumstances, the patients, carers and other services will also adapt themselves to the intervention and behave differently depending on its presence or absence. Variables may assume a different importance for the outcome at different times (see section 4.4.3). Although the quantitative method of logistic regression was able to illustrate that there probably is no one single cause for death at home, this method depends on previous identification of variables, leads us to assume that a variable's contribution is static, takes no account of sequence of events, and in our analysis, no account of interactions. Place of death is unlikely to be the outcome of a linear process, and is probably not a simple sum of all variables involved (Griffiths and Byrne, 1998). An understanding of the interaction of variables and sequence of events may be required so that interventions can be better targeted and their impact better measured.

In spite of these concerns, if randomisation cancels out the impact of everything but the intervention, RCT methodology should still show whether a given variable has an overall effect. However, it will not tell us why and when an intervention works, and therefore when the intervention is futile or how it may be more effective. Although an intervention may be highly effective given a specific set of circumstances, its impact may not be detectable when applied indiscriminately to a large patient sample. Bradley et al (1999) emphasise the need to

integrate qualitative research into trial design to aid the interpretation of quantitative findings and assess their generalisability.

Qualitative research into this area poses problems of its own. Pragmatic considerations may limit qualitative research to retrospective interviews with bereaved carers or to reviews by health care teams. However, prospective studies, preferably including observation, would yield more valid data. The challenge would be to follow several patients and families during a very stressful period. Solutions may be structured data collection supplemented by unstructured recording of events by patients and families themselves using dictaphones or video recorders.

6.4 MEASURING THE QUALITY OF DEATH

The discussion so far leads us to the question whether place of death was the right choice for an outcome measure. There are good reasons for using this variable in palliative care research. It is an easy and reliable variable to measure retrospectively. Data recorded by the Office for National Statistics in the UK and similar institutions in other countries ensure that there is little data attrition for this variable, in contrast with many other measures within this field (McWhinney et al, 1994, Rinck et al, 1997). Past research reviewed in Chapter 1 suggests that statistically home death is more likely than inpatient death to be the outcome desired by patients and carers. Home death can therefore be adopted as an approximate measure for a "good outcome".

However, while Chapter 1 suggests that one half or more of patients may prefer death at home, this still leaves a considerable proportion of patients who do not. Furthermore, Hinton's (1994a) data suggest that preference for home death may decrease as death approaches, and that the patient's family may be less concerned about whether the death itself occurred at home as long as most of the patient's care took place at home. Our qualitative analysis showed that home death was not necessarily the preferred choice for all patients and carers within the RCT sample. It is questionable to use proportions at an aggregate level to imply what constitutes a desirable outcome for the individual. The desirability of the inpatient and home

settings furthermore depends on the circumstances of the particular home or hospital/hospice. Good palliative care can be provided in inpatient settings, particularly in hospices, but also through palliative units or teams within hospitals. These may confer some of the benefits of assumed to be associated with home care, e.g. individualised care, more opportunity for the family to be actively involved, while at the same time giving the security of having medical staff close at hand. Conversely, an inadequately supported death at home can be traumatic for both patients and carers.

Clearly what we would really want to establish is whether the outcome was a "good death" in each individual case, regardless of location. However, because this is far more difficult to assess, home death has been used as a surrogate. What most palliative care services would seek to deliver, home or otherwise, is a "good death", including the best quality of life possible leading up to the death. Home death is only an aim insofar that it is conducive to achieving this.

A method for measuring Quality of Death was developed by Wallston et al (1988). This involved constructing a measure based on patients' views on what constituted a good death (e.g. having loved ones present), with importance (weighting) assigned to items on the basis of the number of patients mentioning it. Bereaved carers were later interviewed to assess how many desirable conditions were fulfilled at the death. The problem with developing such a measure is that the definition of a "good death" is likely to differ considerably between individuals, cultures and religions (Neuberger, 1999). An individualised approach would be possible, but would depend on patients' awareness and willingness to discuss these matters openly. Any such measure furthermore depends on carers' retrospective assessments.

Measuring quality of life (QoL) in the period preceding death offers an alternative solution. Two issues need to be considered: (1) whether such measures capture what is important to patients towards the end of life; (2) the validity of assessments by proxy, as the majority of patients have difficulty completing measures themselves.

It is important for any palliative QoL measure to cover the domains relevant to patients towards the end of life. Some studies suggest that patients self assessments on existential domain items (e.g. life is worth living, existence is meaningful) may be equally or more closely related to overall QoL scores than physical symptoms (Fowlie et al, 1989, Cohen et al, 1995, 1997). A review by Hearn and Higginson (1997) found that no single QoL measure for advanced cancer to date covered physical, psychological and spiritual domains in a format which provided sufficient and reliable information. Work has since been undertaken to develop a measure to address this gap, which awaits further testing and validation (Hearn and Higginson, 1999). The European Organisation for Research on Cancer Treatment (EORTC) is developing a specific palliative module to be used with their generic QoL measure for cancer (Aaronson et al, 1993, Ahmedzai et al, 1994), and these may together offer another means of comprehensive QoL assessment for palliative cancer patients.

The majority of QoL measures suitable for the palliative phase have been developed for cancer patients, and may therefore be specific to cancer. Whilst there are probably features of the terminal phase common to most diseases, which can be measured through a generic measure, disease specific palliative measures may need to be developed for non-cancer diagnoses to enable concerns specific to those patient groups to be reflected (Bowling, 1995).

A potential problem with all standardised measures, however, is that what is perceived as important to QoL towards the end of life may be highly individual. Even good pain control, normally considered essential to quality of life and good palliative care, may not be desirable to some patients if there is a risk of compromising conscious awareness (Neuberger, 1999). Measures have been developed to accommodate individual definitions of quality of life, allowing each patient to choose the aspects of life most important to him/her and rating how well they score on these (O'Boyle 1994, Fraser et al, 1993). However, there is concern whether such measures can be used for comparison between patient groups, precisely because they are specific to the individual.

One further important issue in measurement of end stage QoL is the validity of measurements by proxy. As many patients will be too ill to complete very simple measures even with help (Rathbone et al, 1994, Rinck et al, 1997), palliative care research often has to rely on assessments by proxy, either through health professionals or next of kin. Such assessments may differ considerably from patients' own views. Research suggests that there is more correspondence between patient and proxy assessments for observable or physical variables compared to emotional or unobservable ones (Spitzer et al, 1981, Regan et al, 1991, McMillan and Mahon, 1994, Field et al, 1995, Brunelli et al, 1998). Even so, doctors and nurses tend to underestimate patients' pain severity relative to patients (Higginson and McCarthy, 1993, Larue et al, 1995, Chan and Woodruff, 1997). It appears the more severe the pain the less accurate professionals' assessments (Grossman et al, 1991, Stephens et al, 1997). Family carers on the other hand tend to overestimate patients' pain (Higginson et al, 1990, Ferrell et al, 1991, Clipp and George, 1992, Higginson and McCarthy, 1993, Miaskowski et al, 1997). Carers also tend overestimate patients' emotional distress (Faller et al, 1995, Spiller and Alexander, 1993, Field et al, 1995, Higginson and McCarthy, 1993) and their ratings of the patient's hope and distress may correlate more closely with how the carer is feeling (Faller et al, 1995). Health professionals have both been found to overestimate (Faller et al, 1995, Higginson et al, 1990, Higginson and McCarthy, 1993) and underestimate patients' psychological distress (Ford et al, 1994). Finally, health professionals and carers tend to underestimate the patient's quality of life relative to patient assessment (Slevin et al, 1988, Fowlie et al, 1989, Stephens et al, 1997). If assessment by proxy is used, there is therefore a need to understand when and in what direction patient and proxy assessments may differ, and how one may train assessors to make more accurate assessments. Hearn and Higginson's (1999) questionnaire enables the same assessments to be made both by patients and professionals, thus allowing systematic comparison. Initial results suggests that professionals' perception of the patient's situation on this measure was close to that of the patient (i.e. >80% of assessments within one point of patient's assessment on five point scale for a minimum 70% of items). Further work with this tool should enhance our knowledge of the relationship between patient and professionals' assessment.

If QoL measures are to be used to assess the quality of death, there is a need to ensure that the measures used encompass the issues important to patients towards the end of life. If we have to rely on measurement by proxy, we need to consider the identity of the assessor and try to ensure that likely biases are known and understood.

6.5 CONCLUSION

6.5.1 Implications for research

The HAH evaluation illustrates the difficulties associated with conducting RCTs in palliative care. It furthermore supports the argument for a multi-method approach to evaluation, including the use of qualitative research prior to and during quantitative evaluation (Bradley et al, 1999).

The current evaluation demonstrated the need for gaining extensive knowledge about the intervention, setting and patient group in order to assess the feasibility of conducting an RCT. Knowledge about the patient group and likely recruitment and attrition rates is required to fully assess the likelihood of attaining sufficient statistical power. An understanding of the components of the intervention and its setting is required to ascertain whether one can distinguish sufficiently between the intervention and control condition to justify a trial. Furthermore, as palliative care is typically holistic, flexible and tailored to the individual, there is a need to consider whether a degree of standardisation in care delivery can be achieved, without compromising patient care or the external validity of the trial. Alternatively, if standardisation is not possible, the trial should seek to incorporate procedures for recording the principal components of care delivered to participants. Even if these hurdles can be overcome, ethical and political concerns may still render a trial unfeasible, although careful choice of randomisation design (e.g. patient preference or cluster randomisation) may help ease such concerns in some situations.

If an RCT proves unfeasible, it has been argued that well designed observational studies may provide an acceptable alternative and yield similar results to an RCT, provided the exclusion criteria are similar and we have a good understanding of the prognostic factors (Britten et al, 1998). In the present evaluation,

however, on the basis of the observational study alone, one could easily have concluded that HAH played a greater role in home death than it apparently did, although concerns about case mix effects would remain. Conversely, an evaluation consisting only of the RCT would have left us with considerably less knowledge about the service, its client group and the potential contribution of other factors to place of death. Thus the two methods brought different insights, and the evaluation clearly benefited from the employment of both.

The evaluation would have been further informed by use of qualitative research methods. First, we needed to know more about the processes behind death at home as opposed to death in inpatient care. Qualitative research into this issue would have helped us target the quantitative research better. Qualitative research furthermore could have helped establish which benefits home death may confer on patients and whether the same benefits could be achieved in inpatient hospice settings, e.g. an individualised approach to care. We do not know under which circumstances and for whom home death would be desirable, and at what cost to the informal carers. We need to address these aspects if we are to use place of death as an outcome measure in the future. Place of death on its own, without knowledge of its meaning for the patient or family carers may be of little use in palliative care research. However, an alternative approach of exclusively relying on quality of life measures may also ignore important aspects of a patient's death. The value to patients and carers of death in a particular setting may not be reflected in such measures, e.g. preserving familiar aspects of life, remaining within the community, enabling the family to participate more in care (where death at home is concerned). A better understanding of why home death may be valued, is likely to represent an important contribution to palliative care evaluation.

An important message from the evaluation is the value of a multi-method approach to the topic under investigation. This means regarding observational studies and RCTs, quantitative and qualitative methods as complementary rather than incompatible approaches, each contributing valuable information (Brannen, 1992, Bryman, 1992, Black, 1996, Bradley et al, 1999). The challenge for the researcher is to bring out the strength of each method in addressing an aspect of the research question, keeping in mind the weaknesses of each, and interpreting the results within the limitations of each method.

6.5.2 Implications for further development of palliative home care services

Should one make further investment into palliative home care services within the UK, or indeed other parts of the world? The question is particularly pertinent in the light of the recent NHS Cancer Plan (2000) for England, in which the government states it will match voluntary sector funding for specialist palliative care by 2004. Most palliative care services have been introduced through public and professional enthusiasm and charitable funding, without prior needs assessment or subsequent evaluation. Palliative home care is no exception. In 1995 there were 47 registered "Respite Care at Home or Hospice at Home" services in the UK and Northern Ireland. The number may now have stabilised at around seventy, although lack of an exact definition hampers efforts at establishing exact numbers (St Christopher's Hospice Information Service). Within Cambridge considerable support for such a service among health professionals (Grande, 1994, Barclay et al, 1999), contributed towards securing charitable funding for Cambridge HAH. Despite the considerable number of hospice at home services created, the research embodied in this thesis represents perhaps the first robust evaluation of hospice at home. This evaluation suggests it is by no means clear that further funding should be invested in such services, and that the decision would depend on the aims of the hospice at home service, its target group and the existing service context into which it will be introduced. The evaluation clearly points to the need for careful consideration of these factors prior to new service developments, and rigorous evaluation once such services are introduced.

For those funding hospice at home services the desired aims may differ depending on standpoint. Commissioners of services are likely to look to a new service to free up other health care resources and/or reduce costs of care delivery, whilst achieving equal or improved quality of care; or otherwise to fill a hitherto unaddressed gap in provision at a reasonable cost. Charities are likely to look to a service to improve quality of care for its clients overall and perhaps be less concerned about costs to the health care system in general. Service providers and health professionals presumably would seek to attract funding to improve the range and quality of care delivery to clients (although other motives such as improvement of the status and reach of their organisation or profession may play a part).

It is not clear, however, that any of these aims were achieved by Cambridge HAH, nor that they would necessarily be achieved by hospice at home services elsewhere. Cambridge HAH did not appear to shift the balance of care from secondary to primary care, thus releasing pressure on inpatient beds. First, it did not appear to change location of death, our key outcome variable. Neither did HAH increase patients' likelihood of spending time at home in their last two weeks of life, as reported by health professionals (Grande et al, 2000). Furthermore, it is not clear that the service reduced use of inpatient care overall. In the case control study (Chapter 2) patients admitted to HAH were less likely to have inpatient hospice care compared to patients referred but not admitted to HAH. However, those admitted to HAH were more likely to have inpatient hospice care than those never referred to HAH. RCT patients admitted to HAH were, if anything, more likely to receive inpatient hospice care and had more hospice inpatient days than those not admitted to HAH (both $p<0.07$, Chapter 4). There were otherwise no difference in use of inpatient care between patients admitted to HAH and other patients.

Even if HAH did shift the balance from secondary to primary care, HAH is unlikely to represent a cheaper alternative to inpatient care. For policy makers there has been an overall drive towards community care motivated by a belief that this involves cost savings compared to inpatient care (Benjamin, 1993). However, research into hospital at home, palliative or otherwise, yield different results on costs depending on the setting, service and analysis used (Shepperd, 1999). The considerable range of care packages and care settings in the present evaluation placed analysis of cost outside its scope. However, it is unlikely that Cambridge HAH, with its high nurse to patient ratio, represented a cheaper alternative to inpatient care. Palliative care does not involve a simple, time limited, nursing procedure which can be delivered to a high number of patients within a reasonable time period. It requires the presence of an experienced nurse over time, particularly during nights. Any home care alternatives are furthermore likely to involve considerable cost to informal carers in time, effort and loss of income.

However, HAH may have released other primary care resources. RCT patients allocated to Cambridge HAH had fewer out of hours GP visits than controls in the penultimate week of life (Grande et al, 2000). However, the data do not suggest that HAH otherwise was associated with reduced NHS community

nursing service use. On the contrary, HAH patients were the highest users of such services. In the case control study patients admitted to HAH were more likely to have Marie Curie nursing and had more hours of district nursing than patients referred but not admitted (Chapter 2). RCT patients eventually admitted to HAH were also more likely to have Marie Curie input than those not admitted (Table 4.8), and received more district nursing, Marie Curie and Flexible Care hours (Table 4.9). It is still possible that HAH did help release other community nursing resources, and that the difference in such service use between HAH patients and other patients would have been even greater without HAH input. The study approach did not allow proper assessment of potential shifts in resource use within the NHS locally. Furthermore, HAH may have reduced demands on social services or decreased reliance on British Nursing Association care, often paid out of patients' and carers' pockets. It was not feasible in the present study to collect data on care outside the NHS. Nevertheless, apart from GP input, our data suggest that introduction of Cambridge HAH may have been associated with an accumulation of community nursing care on a few patients, rather than a better distribution of care resources. Whenever there was a difference in community service use, HAH patients were more likely to have other services and more of them than other patients.

If HAH did not release resources within other services, its introduction is likely to have represented an overall increase in cost. However, money is arguably worth spending if it increases quality of care or addresses a clear gap in service provision. There was evidence that HAH improved quality of home care in the last two weeks of life. In the RCT GPs, district nurses and informal carers assessed HAH more favourably than standard care on symptom control and adequacy of care (Grande et al, 2000). However, HAH may not have improved quality of care for palliative care patients overall. It may rather have represented added benefit for a privileged few, thus its value may still be questionable. Our data suggested that HAH may not have reached the patients with the greatest capacity to benefit, because of having a poorer starting position. Locally, HAH may have been a costly means of improving care for those already at an advantage in care support.

Nevertheless, HAH can be argued to have attempted to address a clear gap in service provision, namely proper night care and continuous, hands-on support (Grande, 1994). However, this was an area already

addressed by other services, in particular Marie Curie nursing, albeit insufficiently so. If the same amount of money were used to boost existing services, it is possible this may have provided greater benefit for the same cost, particularly as it would not involve the start-up costs associated with a new service.

In summary, it does not appear that HAH enabled more patients at home or released secondary care resources. Even if it did, hospice at home is unlikely to represent a cheaper alternative to inpatient care. HAH did not appear to release other community care resources apart from a small number of GP out of hours visits. Although it may represent better quality home care, it may only have reached a privileged few with less capacity to benefit than other patients. The area of need addressed by the service was already covered by other services, albeit insufficiently so.

The evaluation suggests that prior to creation of new hospice at home services, it is necessary to give careful consideration to the features of the proposed service itself, its target group and the existing service context. Hospice at home is unlikely to release other care resources unless specifically designed to do so, e.g. if specifically targeted towards enabling discharge, or if introduction of the service stipulates exclusion of other community care (Shepperd, 1999). The present evaluation illustrated that a wholesale introduction of a hospice at home service without consideration of existing service context and target group may lead it to have little or no impact on outcome, in our case place of death.

If there is already a high level of service provision locally, there may be little further gain in introducing additional services. If so, one needs to consider whether funding is better invested in other, more service deprived areas. Alternatively, if further funding is to be invested in an area with good existing service provision, consideration should be given to whether a similar or better effect can be achieved by boosting existing services, avoiding the start-up costs of a new service. This is particularly the case if the new service is not qualitatively different from existing services in its target group or function. One may also consider development of services addressing qualitatively different types of problem to existing services (e.g. a multidisciplinary, specialist outreach team to tackle complex problems, not addressed by experienced nursing care), rather than creating a new service to fulfil the same function

Prior assessment of the target group for the service is also important. We are likely to observe less impact of a new service if it is provided for those who are already managing well, whether through own resources or external provision. There may be a case for specifically targeting patients who are likely to derive the most benefit from additional input, i.e. yield maximum return on investments (e.g. those with the least home resources, who live alone). If such specific targeting is not ethically, politically or practically feasible, effort is still required to counteract the biases apparently inherent in referrals to palliative home care, i.e. biases which favour the young, the educated and well off who already have good service provision. Such biases are again likely to reduce the gains which can be derived from added input (Britten et al, 1998). This may require educating the health professionals who make the referrals and proactive monitoring of clients likely to slip through the care net.

Our evaluation furthermore shows the need for evaluation of a service once it is established. A service's actual, rather than assumed, impact needs to be assessed. Cambridge HAH illustrates this point well in that it did not achieve an increase in home deaths although it was assumed that it would.

Finally, our evaluation suggests that if death at home remains an aim for future palliative home care services, the key challenge may be to sustain home care over a longer period. Patients who began their home care early were less likely to remain at home. This implies that greater emphasis should be placed on respite care, early introduction of support for informal carers and longer term care options to prevent exhaustion of informal care resources. Conversely, a service targeted towards the last two weeks of life, like HAH, may be unlikely to have an impact on place of death, as it is most likely to reach patients destined to die at home anyway. It is clear, however, that we still have a considerable lack of knowledge of the factors precipitating inpatient death. Further work is required to identify the main difficulties in achieving home death. These should subsequently be specifically targeted, whether this relates e.g. to sustaining long term home care or achieving end stage discharge from secondary care.

In summary, further service development requires careful consideration of what a new service is expected to achieve, its client group and how it fits within the existing service context. This may involve choosing not to create new services in areas with already high care provision, and possibly rather investing in existing services. It may furthermore involve attempts to address bias in care delivery. Positive discrimination may be required to introduce services to those patients with the most capacity to benefit and to achieve a distribution of care resources, rather than an accumulation of services on a few patients.

Good palliative home care is unlikely to represent a cheap alternative, and it is important that available funding is spent wisely. Providers may have been all to willing in the past to welcome charitable pump-priming of palliative care services, and charities to provide it, without proper assessment of the likely benefits and the long term, possibly unjustified, costs to the health care system. Now that the government has promised to invest £50 million into palliative care in England (NHS Cancer Plan, 2000), it would seem pertinent to allocate a proportion of this amount to properly funded, national multi-centre trials to assess the likely impact of palliative home care within different service contexts and patient populations (Salisbury and Bosanquet, 2000), adopting a multi-method approach (Bradley et al, 1999). Without proper forethought and evaluation, considerable amounts of money may easily be spent on palliative care with little effect, e.g. on offering a top class service to an already privileged few.

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APPENDIX 1: Literature review

PAGE

NUMBERING

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APPENDIX 1

Table 1.1 Studies of variables associated with death at home, all diagnoses (positive relationship +, negative relationship -, no significant relationship found 0)

Study	Subjects	Method	Variables
Cartwright, Hockey and Anderson (1973)	Random sample of 960 adult (>=15) deaths from twelve registration districts in England and Wales in 1969. 785 (82%) bereaved carers interviewed.	Retrospective interviews with informal carer or official. Mainly chi-square tests.	**Informal support:** living alone-, married+, children +, daughters +; **Diagnosis:** cerebrovascular disease-, respiratory disease-, ischaemic heart disease and other circulatory disease +; **ADL:** patient restrictions -, bedridden -; **Symptoms:** pain -, confusion -, vomiting+, loss of appetite+, bedsores+, dyspnoea+; **Time period:** length of need for self care and night care -; **Age:** below 45 -, 85 or above -; 45-54 years of age +, **Sex:** female -; **Social class**: 0; **Other:** district nurse support+, awareness of condition or outcome 0
Bowling and Cartwright (1982)	Random sample of 1600 deaths from eight representative areas in England. All married women >=60 and all married men >=65 were identified. 361 (74%) bereaved spouses interviewed	Retrospective interviews with bereaved spouse. Mainly chi-square tests.	**Informal support:** carer is wife rather than husband +; **Diagnosis:** bronchitis +; ischaemic heart disease +, pneumonia -, influenza -; **Sex:** female -; **Other:** spent time in hospital during last year of life -
Rosenberg and Short (1983)	All deaths age >= 65 in Whatcom county in 1971, 1975 and 1978 (n=543-807), in King County in 1971 (n=10,213), Detroit 1971 (n=20,203) and Springfield, Illinois in 1975 (n=777).	Mortality and death certificate data. Chi-square.	**Sex:** female -; **Other:** white versus non-white -
Polissar, Severson and Brown (1987)	All 426115 deaths of residents in a US state 1968-1981 inclusive.	Data from death certificates. Cross-tabulation of results.	**Informal support:** divorced+; **Diagnosis:** heart and vascular disease+, cerebrovascular disease (including stroke)-, pneumonia and influenza-; **Age:** 75 or above-; **Sex:** female-; **Social class:** percentage of high school graduates in area of residence 0; **Other:** white-, urban residence 0
Hunt, Roder, MacHarper (1989)	All cancer deaths in selected South Australian suburbs in 1981 (n=432) and 1986 (n=609), selection of next registered cancer death for resident in other suburb (n=2082), random sample of 2643 non-cancer deaths	Data from death certificates. Chi-square and unconditional logistic regression.	**Sex:** female -;

APPENDIX 1

Table 1.1 Studies of variables associated with death at home, all diagnoses (continued)

Study	Subjects	Method	
Hunt, Bond, Groth and King (1991)	Records from funeral directors representing half the deaths in a South Australian city. 20% of deaths randomly sampled every 10th year from 1910 to 1980 inclusive, and 1987. n=2566 deaths.	Data from funeral director records. Chi-square and logistic regression.	**Informal support:** partner +, number of children +?*; **Diagnosis:** non-cancer +; **Age:** over 65 0; **Sex:** female -; **Social class:** unskilled +?*; **Other:** urban residence +?* *Paper considers different inpatient settings separately. For some variables chi-square can be recalculated, comparing home deaths with inpatient deaths overall. Otherwise significance of variable's relationship to home death is unclear
Clifford, Jolley and Giles (1991)	All deaths registered during a three month period in 1988 in Victoria, Australia (n=7697)	Retrospective data from the office of the Registrar of Births, Deaths and Marriages. Descriptive percentages and logistic regression.	**Informal support:** married+; **Diagnosis:** cancer versus circulatory disease +?, stomach cancer versus other cancers +; **Age:** >65 -, **Sex:** female -; **Social class:** socioeconomic area of residence 0
Seale and Cartwright (1994)	Random sample of 800 adult (>=15) deaths from ten local authority areas in England in October and November 1987. 639 (80%) bereaved carers interviewed	Retrospective interviews with informal carer or official. Tests of differences in proportions or chi-square tests.	**Informal support:** living alone -; **Age:** 75 or above -; **Sex:** female -; **Social class:** 0
Seale, Addington-Hall and McCarthy (1997)	461 cases in which both patient and carer knew patient was dying and this was considered positive, and 150 cases in which patient did not know he/she was dying. Identified from retrospective interviews with 3696 people who knew the deceased well, representing 69% of a random sample of deaths in 20 health authorities in England 1990.	Structured retrospective interviews. Chi-square and multivariate logistic regression	**Other:** open awareness of death +
Brock and Foley (1998)	1227 cases from a stratified sample of 1500 of all deaths of patients aged >=65 between October 1984 and September 1985 in Connecticut Health Service Area.	Death Certificate data. Percentages reported only.	**Age:** >85 -; **Sex:** female age 65-84 versus male age 65-84 -

APPENDIX 1

Table 1.2 Studies of variables associated with death at home, cancer patients (positive relationship +, negative relationship -, no significant relationship found 0)

Study	Subjects	Method	Variables
Parkes (1978)	276 of 435 spouses, aged <65, of cancer patients aged <65 who died in two London boroughs 1967-1971. Analysis of 100 patients who died in hospital and 65 patients who died at home or spent all but last week at home. Patients without identifiable terminal period or who died in hospice excluded.	Post bereavement interview with carers. Chi-square.	**Informal support:** age of carer 0; **ADL:** mobile+; **Symptoms:** initial pain-; pain in final phase +; confusion -; **Sex:** 0; **Social class:** social class 0
McCusker (1983)	All 2989 adult (>=15) residents who died in a US County 1976-1978, whose cancers had been diagnosed before death and with known place of death and socio-economic area (unknown for 9.7% of initial sample).	Data from regional tumour registry and census data. Odds ratios estimated from logit model analysis.	**Diagnosis:** leukaemia-, lymphoma -, colorectal+, genitourinary +; **Time period:** survival (mainly >1 month) +; **Age:** 0; **Sex:** 0; **Social class:** high socioeconomic area of residence+; **Other:** ethnic background 0
Polissar, Severson and Brown (1987)	Further analysis of Polissar et al, Table 1. All cancers newly diagnosed in 13 US counties 1974-1981 which could be linked with death certificate information. N=33865	Data from Cancer Surveillance System. Cross-tabulation of results.	**Diagnosis:** non-Hodgkins lymphoma-; **Time period:** survival<1 month-
Roder, Bonnett, Hunt and Beare (1987)	Random stratified samples of cancer patients from South Australian death records for 1981 (n=795) and 1985 (n=787).	Retrospective records. Chi-square.	**Informal support:** married men versus unmarried +; **Diagnosis:** haematological cancer-; **Age:** 0; **Sex:** female -; **Social class:** resident in affluent suburb+
Moinpour and Polissar (1989)	All 28828 residents of 13 Washington state counties who died 1980-85 with cancer as primary cause and diagnosis made prior to death. Values for all variables obtained for 26500 (92%) patients for logistic regression analysis.	Data from existing population, cancer surveillance and service provider records. Calculation of relative risk and logistic regression.	**Informal support:** married +; **Time period:** survival<1 month -; **Age:** 85 or above -; **Other:** non-urban residence +
Hunt, Roder and MacHarper (1989)	Further analysis of Hunt, Roder and MacHarper, Table 1, cancer patients only.	Data from death certificates. Chi-square and unconditional logistic regression.	**Informal support**: number of children +, married men versus unmarried +; **Age:** -; **Sex:** female -; **Other:** Australian-born female -
Johnson and Oliver (1991)	All cancer deaths 1977-1988 in UK health district, ranging from 444 to 712 deaths per year. Similar data obtained for surrounding health districts for 1977, 1982 and 1987	Cancer Registry data. Chi-square .	**Diagnosis:** primary cerebral tumour -, ovarian cancer +; **Social class:** disadvantaged health district+?

APPENDIX 1

Table 1.2 Studies of variables associated with death at home, cancer patients (continued)

Study	Subjects	Method	Variables
Hunt, Bonett and Roder (1993)	All deaths attributed to cancer in South Australia for whom place of death was known (n=2715)	Retrospective data from the Central Cancer Registry and the Registrar General of Births, Deaths and Marriages. Unconditional multiple logistic regression.	**Diagnosis:** haematological malignancy -, upper gastrointestinal malignancy+; **Time period:** survival 0; **Age:** 70 or above-; **Sex:** female -; **Social class:** high or middle socioeconomic area of residence +; **Other:** country of birth 0, Aboriginal +
Costantini, Camoirano, Madeddu, Bruzzi, Verganelli and Henriquet (1993)	All 12343 dult (>17) cancer deaths in Genoa 1986-1990.	Linkage of data from death certificates, general registry office and home care service records. Univariate odds ratio, multivariate logistic regression.	**Informal care:** married +; **Diagnosis:** leukaemia/lymphoma-, head/neck-, lung -, prostate +; **Age**: +; **Sex:** female +; **Social class:** education level +
Higginson, Webb and Lessof (1994)	All cancer deaths in 44 electoral wards in London during 1988-1992.	OPCS data, Underprivileged Area (UPA) score calculated with 1991 census data. Spearman's correlation between proportion of home deaths and UPA score.	**Social Class:** High Underprivileged Area score -
Axelsson and Christensen (1996)	All 203 patients who died in a Swedish county of cancer of the GI tract, uritogenital organs, the breast, the skin or the thyroid.	Data from death certificates, medical records and parish registries Chi-square.	**Informal support:** married 0; **Diagnosis:** 0; **Time period:** survival< 1 month -; **Age:** 0; **Sex:** 0; **Other:** distance to hospital 0
Sims, Radford, Doran and Page (1997)	All cancer deaths among Doncaster (UK) residents in 1995 for whom former occupation was known (99%, n=820).	Retrospective data from the Office of National Statistics. Chi-square.	**Social class:** skilled workers (III) versus highest (I & II) and lowest social class (IV and V) +
Karlsen and Addington-Hall (1998)	Random sample, stratified by age and social class, of 229 cancer deaths in an inner London Health authority 1995-1996, representing a response rate of 53%.	Post bereavement postal questionnaire or interview with people who registered the death. Chi-square, t-test and multivariate logistic regression.	**Informal support:** carer found caring rewarding +; **Symptoms:** good home pain control +; **Age:** >65 - ; **Sex** 0; **Social class:** 0, but of those who wished to die at home, classes I-IIIN most likely to do so; **Other:** preferred home death +; GP care 'poor' -, community or palliative home nursing +, special equipment +, needed help with shopping, transport, cooking -, attendance allowance +, inpatient stay -

APPENDIX 1

Table 1.2 Studies of variables associated with death at home, cancer patients (continued)

Study	Subjects	Method	Variables
Higginson, Astin and Dolan (1998)	All 1.3 million cancer death registrations in England 1985-1994	ONS Death Certificate data. Chi-square	**Diagnosis:** lung, colorectal, bone or connective tissue, head/neck cancer +, haematological or breast cancer - ; **Age:** >75 - ; **Sex:** female -
Higginson, Jarman, Astin and Dolan (1999)	All 1.3 million cancer death registrations in England 1985-1994, as above	ONS Death Certificate data, Jarman UPA and Townsend deprivation scores for electoral ward (1991 census). Pearson correlation coefficients, multiple regression analysis	**Diagnosis:** digestive organ cancer +; **Age:** >65- ; **Sex:** female -; **Social class:** high UPA or Townsend index score -; **Other:** proportion of ethnic minorities -
Jordhøy, Fayers, Saltnes, Ahlner, Elmquist, Jannert, Kaasa (2000)	434 of 707 cancer patients referred to Norwegian Palliative Medicine Unit, age >=18, life expectancy 2-9 months, able to give consent and complete QoL measure. Haematological malignancies and participants in other trials excluded. 235 intervention and 199 control patients.	Cluster randomisation (3 pairs of clusters stratified on location of residence and age) Univariate and multivariate logistic regression with 'bootstrap estimate'.	**Informal support:** living with spouse +, informal help +; **Diagnosis:** 0; **Age:** - ; **Sex:** female -; **Social class:** 0; **Services:** conventional home care -

APPENDIX 1

Table 1.3 The association between home care and home death: type of home care service and place of death

Study	Subjects	Method	Home care service
Mor and Hiris (1983)	Described below	Described below	26 hospices of three types: Hospital based, home-health agency based and free standing (not part of any other health provider). No details. All hospices provided home care. Death at home: 20% of patients in hospice with beds, 64% in hospice without beds.
Zimmer et al (1983)	45 patients who died during RCT of home support for chronically ill and terminal patients, who wished to remain at home, were homebound, needed primary medical care and had a carer.	Randomised controlled trial. Comparison of percentages, no significance testing reported	Home care team consisting of a nurse, physician and social worker providing home visits and a 24 hour telephone service. Death at home: 71% in the home care group and 47% in the control group.
Greer et al (1986)	Described below	Described below	Conventional care sites (14) compared with hospices with beds (19) and hospices without beds (20). No details. All hospices provided home care. Death at home: 13%, 27% and 62% respectively. No detailed description of care, presumably too many sites compared.
Moinpour and Polissar (1989)	Described above, 6762 patients had hospice care	Described above	Hospice without beds, hospice with beds and conventional care. No details. All hospices provided home care. Death at home: 41-53% of home based hospice patients, 25%of inpatient based hospice patients, 16% of non-hospice patients,
Ward (1987)	Patients referred to home care services in York and Trent regions: 4 hospice based and 4 home care only. >100 patients for each site, 957 total (10-34% of patients dying of cancer in relevant health districts)	Percentages, no significance testing	Hospice based home care: office in 25-36 bed unit, 2-2.5 WTE nursing staff, medical advice available, some with social worker and 24 hour access. Home care based: no inpatient link, 2-4 WTE nursing staff, 24 hour access, some with social worker and medical advice Death at home: 29% of hospice based patients, 65% of home care only patients 2-3% home death decrease in areas with hospice based care. 0-4% increase in areas with home care only.
Komesaroff et al (1989)	Described below	Described below	Home care programme with an on-call after-hours system caring for approximately 25 patients at any time. Medical staff members supplied from local hospital, and services provided "include nursing and medical care, counselling and other forms of support". 51% of home care patients died as inpatients compared to 95% of patients allocated to hospice

APPENDIX 1

Table 1.3 The association between home care and home death: type of home care service and place of death (continued)

Smith, Eve and Sykes (1990)	116 (74%) of 156 inpatient units listed in 1990 Directory of Hospice Services in UK and Ireland. 115 (36%) of 321 home care teams.	Postal survey of services. t-test and Mann-Whitney U-test	Of 115 home care teams 78% had less than 5 WTE nurses, 53% had a doctor, 42% a social worker Median home death rate: 30% for home care teams with beds, 37% of teams without beds
Dunphy and Amesbury (1990)	Described below	Described below	Home care team linked to hospice, compared to the hospice's inpatients. Team consisting of six nurses, three doctors and two social workers covering a population of 0.5 million. Routine visits 2-3 times a week, but max 2-3 visits a day possible with close liaison with DN. Night sitters can be provided. Team doctors provide 24 hour availability, visiting at night when necessary. Of patients referred to the home care team 61% died at home and 39% in inpatient care; 91% of the hospice patients died in hospice and 9% discharged (place of death not reported)
Johnson and Oliver (1991)	Described above	Described above	Home symptom control team consisting of a consultant in palliative medicine, five nursing sisters, a social worker and "other disciplines as necessary". Their role is to advise on medication, responsibility for prescribing remaining with the GP. Introduction of home symptom control team was followed by a transient rise in cancer home deaths locally (approximately 10 percentage points) which was not sustained after the third year
Costantini et al (1993)	Described below	Described below	Home care service consisting of 12 physicians, seven registered nurses, three psychologists and 25 volunteers. Cooperating closely with the family physician. Each patient assisted by a physician, supported by other members of the team. Physicians available 24 hours a day including holidays. Home death twice as likely among home care users as non-users. Increase in home death locally from 27.9% to 33.0% following introduction of home care service.
Thorne et al (1994)	1022 of 1055 cancer deaths in people aged 16 or over in Exeter Health District May 1991 – April 1992.	Retrospective information from death certificates Student's t test, chi-square	Domiciliary hospice service providing nursing support (up to 24 hour), social worker and volunteers network support. 12 general practitioner community hospitals totalling 428 beds. Death at home: 29% of patients whose GP had access to community beds, 41% of patients whose GP had no such access. In areas with GP access to community beds there was no difference in home death between patients whose GP had access to domiciliary hospice care and patients whose GP did not (both 32%).

APPENDIX 1

Table 1.3 The association between home care and home death: type of home care service and place of death (continued)

Sessa et al (1996)	Described below	Described below	Home care programme consisted of collaboration between community nurses, family doctors and social workers, specialists (physicians and nurses) from the cancer centre. Coordinated by nurse at the oncology outpatient clinic, weekly meetings held with community nurses. Death at home: 43.5% under the home care programme, 11.0% outside the programme.
Hinton (1996)	Patients referred to St Christopher's home care team 1984 to 1992	Quasi-experimental Percentages with confidence intervals	Home care team 1984-88 consisted of 4-5 full time nursing sisters, secretarial staff, a hospice consultant physician and registrar (both part time in home care), with other hospice staff contributing if requested; some day care facilities were available. Visits, assessment and advice. 24 hour on-call service. A combination of service changes (nurses being more specifically allocated to individuals in one area, allocation retained but in two separate teams with social worker attached, day hospital facilities added) were associated with a significant increase in home deaths among patients referred from 27% prior to 1988 to 34% in 1990-92.
Smeenk, de Witte, van Haastregt, Schlipper, Biezmans, Crebolder (1998)	79 patients admitted to transmural home care programme, 37 patients in adjacent geographical area not admitted	Quasi-experimental prospective. Mann-Whitney U test and chi-square	Home care programme included a specialist nurse coordinator, 24 hour telephone service, specialist consultant advice, home team consisting of hospital casualty and day care nurses, a home care dossier and care protocols. The home care group had fewer days of rehospitalisation than the intervention group (5.8 versus 11.5 days) and more deaths at home (81% versus 65%), although the latter difference failed to reach significance ($p=0.06$).
Rosenquist, Bergman and Strang (1999)	All 108 cancer deaths in 1992 within area covered by home care team	Percentages	Hospital based home care team. 24 hour access 7 days a week. At least two registered nurses and one auxiliary nurse on every shift, one occupational therapist and at least one senior physician during day. Percentage of home deaths higher than in surrounding districts, 40 of 42 home deaths in the area had team support.
Jordhøy, Fayers, Saltnes, Ahlner, Elmquist, Jannert, Kaasa (2000)	Described above	Percentages and logistic regression	Outreach team based at Palliative Medicine Unit, operating during daytime hours. Team consisting of two palliative care nurses, physician social worker, chaplain, nutritionist and a physiotherapist. Coordinated care with primary care staff, provided advice and education, joined primary care team on home visits. 25% of patients in the intervention group and 15% of controls died at home. Adjusted multiviariate logistic regression (using 'bootstrap estimation') showed controls to be significantly less likely to die at home.

APPENDIX 1

Table 1.4 Variables associated with referral to home care, cancer patients (positive relationship +, negative relationship -, no significant relationship found 0)

Study	Subjects	Method	Variables
Mor and Hiris (1983)	US National Hospice Study data. 3257 adult patients who died in 26 hospices Aug. 1981-Nov. 1982, and were admitted before July 1982. Hospices were home based, hospital based or free-standing	Retrospective, hospice records. Univariate analysis and discriminant function analysis.	**Informal support:** living alone -, carer employed -, carer lives elsewhere -, carer is old- ; **ADL:** functionally dependent -; **Social class:** education level +, income > $10000 +, private insurance -
Evans and McCarthy (1984)	125 patients referred to a London terminal support team compared with all local cancer deaths. Support team worked both in community and hospital and had no designated beds	Research record system for admitted patients; OPCS deaths and 1981 census data. Chi-square .	**Diagnosis:** oropharyngal +, lung +, gastrointestinal -, breast -, haematological cancer-; **Age:** - ; **Sex:** 0
McCusker (1985)	54 home care users and 68 non-users, aged >18, who were diagnosed >= 2 weeks before death and not permanently institutionalised. Randomly selected from all 220 cancer deaths in US county December 1979 and January 1980.	Interviews with patients' physician and closest surviving relative. Chi-square, t tests and analysis of variance.	**Informal support:** married +, spouse as primary caregiver+; **Symptoms:** pain severity at onset of *TCP: 0; **Time period:** TCP > 45 days +; **Functional status during TCP:** 0; **Age:** over 65-; **Sex:** 0; **Other:** spending main part of TCP at home + * terminal care period (TCP): evidence of progressive malignancy, therapy would no longer prolong survival, care directed towards symptom control.
Mor, Wachtel and Kidder (1985)	US National hospice study data Oct. 1980-Sept. 1982. All 5912 cancer patients referred to 8 home based (n=2466) or 9 hospital based hospices (n=3446) for whom both modes of care existed within 30 miles. 3500 patients from demonstration hospices for analysis of inpatient stays.	Retrospective, patient records. Logistic regression. t-tests for comparison of pre-hospice inpatient stays.	**Informal support:** living alone -, carer is male- , carer is employed -; **ADL:** 0; **Symptoms:** required intravenous care-, required bowel or bladder care -; **Age:** 0; **Sex:** female +; **Other:** length of pre-hospice hospital stays -, white -
Greer, Mor, Morris, Sherwood, Kidder and Birnbaum (1986)	US National Hospice Study data Aug. 1981-March 1983. Random selection or census of patients from 20 hospices with home care only (n=833), 19 hospices with beds (n=624) and 14 conventional care sites (n=297). Patients had metastases, an adult primary carer and, for conventional care patients, a Karnofsky score <=50 and poor prognosis.	Interviews with patient and primary carer on entry, 7 day follow up, 2 weekly follow up, bereavement interview 3-6 months after a death. Logistic, linear and weighted least square regression.	**Informal support:** living alone -, carer employed -, married 0; **ADL:** poor Karnofsky score (10-30) -, functionally impaired -; **Time period:** survival 0, length of stay +; **Age:** 65 or above +; **Social class:** income <$10000 -; **Other:** hospitalisation in the two months previous to study -

APPENDIX 1

Table 1.4 Variables associated with referral to home care, cancer patients (continued)

Study	Subjects	Method	Variables
Gray, MacAdam and Boldy (1987)	98 home care patients on cancer registry in 1983 and 98 other cancer registry patients matched on age, sex and site of primary cancer, both diagnosed after August 1981 in Perth, Western Australia.	Cancer Registry, Health Department and hospital records. Analysis of variance.	**Informal support:** married 0; **Time period:** survival+; **Social Class:** socioeconomic area of residence 0; **Other:** length of time in hospital during last month -
Powers and Burger (1987)	US National Hospice Study data 1981-82. Sample as for Greer et al. (1986) with patient prognosis < 6 months. Hospices with home care only (n=827), hospices with beds (n=612) and conventional care sites (n=293).	Data collection as for Greer et al. Univariate and discriminant function analysis.	**Informal support:** living alone -, married +, number of people for helping +, family closeness +; **ADL:** disabled -; **Symptoms:** required intravenous support -, required catheter -, weight loss +, appetite change +, cold sweats +, calm +, happy +, lonely -, frightened -, apathetic - ; **Time period:** length of stay +; **Age:** +; **Carer problems:** carer stress +, time commitment +, loss of income+, carer happy +, burdensome patient +
McCusker and Stoddard (1987)	Cancer patients aged <65 who died in US county 1975-1982. Health insurance members who had made claims in the 6 months before death, and died at least one month after diagnosis. Insurance members represented 74% of all cancer deaths. 857 had used home care (hospice or conventional) and 1017 had not	Quasi-experimental time series evaluation of expanding home care program. Chi-square. Means ANOVA tested, logarithmic transformation of cost variables, square root of utilisation.	**Informal support:** married 0; **Diagnosis:** breast +, genitourinary +, leukaemia -, lymphoma -; **Time period:** survival +; **Age:** 0; **Sex:** female +
Komesaroff et al (1989)	243 patients allocated to hospice inpatient care (n=108) or home care (n=135) in a city in Victoria, Australia, by doctor or social worker independent of study. Patients had three month prognosis, and, for home care, residence within 20 km of care base.	Prospective, data recorded on admission. Statistical method not stated.	**Informal support:** married +; **Diagnosis:** 0; **Time period:** survival from referral+; **Age:** 70 or above - ; **Sex:** 0; **Social class:** professional or non-manual occupation +, private insurance +, pensioner -; **Other:** specific cancer therapy not appropriate-
Dunphy and Amesbury (1990)	547 patients of a London hospice referred to the hospice's inpatient (n=404) or home care service (n=143) during six months.	Retrospective review. Chi-square.	**Informal support**: married +; **Diagnosis**: lung +, CNS tumours -; **Symptoms:** dyspnoea +, anxiety/depression at presentation +; **Time period:** survival from admission +; **Age**: young female +

APPENDIX 1

Table 1.4 Variables associated with referral to home care, cancer patients (continued)

Study	Subjects	Method	Variables
Bradshaw (1993)	Random sample of patients referred over six months to a home care service, free-standing hospice or palliative care unit in a teaching hospital in Perth, Western Australia, who died within a 6 month period. n=60 from each site, total n=176	Retrospective study of patient records. ANOVA with SNK tests, Chi-square.	**Informal care:** has primary carer +; **Diagnosis**: 0; **ADL:** needing help with ADL -; **Symptoms:** bowel and bladder problems, confusion, seizures, wound dressings and pressure area care -; **Age:**-; **Sex:** 0; **Social class**: health insurance 0
Costantini, Camoirano, Madeddu, Bruzzi, Verganelli, Henriquet(1993)	Further analysis by Costantini et al, table 2, of 541 patients who received support from a palliative home care service and 11802 who did not.	Linkage of data from death certificates, general registry office and home care service records. Chi-square.	**Informal care:** married +; **Diagnosis:** lung +, breast +, prostate +; **Age**: - ; **Sex:** 0; **Social class:** education level +
Sessa, Roggero, Pampallona, Regazzoni, Ghielmini, Lang, Marx, Neuen-schwander, Pagani,Vasilievic, Cavalli (1996)	993 of 1223 cancer patients who died in Swiss region between January 1991 and July 1993, who were resident in the area and for whom the region's referral centre for medical oncology was in charge of treatment. 317 participated in home care program.	Retrospective review of clinical records, enquiry to patient's last address for missing data. Chi-square and Kruskal-Wallis tests.	**Diagnosis:** haematological malignancy -, breast -; **Age:** 0, **Sex:** 0, **Other:** number of hospitalisations-, median length of hospital stay in last 3 months -, median months contact with the medical oncology centre +
Hunt and McCaul (1996)	All 2800 cancer deaths in South Australia in 1990, of which 1561 had hospice involvement (home or inpatient)	Central Cancer Registry data and State death records. Logistic regression.	(Referral to hospice whether home or inpatient:) **Informal support:** married +; **Diagnosis:** haematological cancer -; **Time period:** survival > 6 months+; **Age:** - ; **Sex:** 0; **Other:** born in UK or Europe+, rural residence-
Talmi, Bercovici, Waller, Horowitz, Adunski and Kronenberg (1997)	All patients with terminal head and neck cancer admitted to inpatient hospice program in Israel between 1988-1994 (n=102) or home hospice program 1990-1994 (n=24).	Retrospective survey of patient charts. Statistical method not stated, means, frequencies and percentages provided.	**Diagnosis:** oral cavity tumour -; **Symptoms:** pain severity on admission-, oral candidiasis -, weight loss-; **Time period:** survival from diagnosis: 0, survival from admission: +; **Age:** -; **Sex:** 0

APPENDIX 1

Table 1.4 Variables associated with referral to home care, cancer patients (continued)

Study	Subjects	Method	Variables
Eve, Smith and Tebbit (1997)	All services known to the UK Hospice Information Service 1995 approached. Responses from 138 (75%) of 186 inpatient services and 235 (68%) of 347 home care services analysed. Patient details obtained from 31-52% of all inpatient and 27-43% of all home care services.	Questionnaire about services provided and patient details. Tables of percentages.	**Diagnosis:** cancer 0; **Age:** above 65-; **Sex:** 0; **Other:** ethnicity 0
Hunt and McCaul (1998)	All cancer deaths in South Australia in 1990 (n=2800) and 1993 (n=2873), of which 3374 had hospice involvement (home or inpatient). Extension of Hunt and McCaul (1996).	Central Cancer Registry data and State death records. Logistic regression.	(Referral to hospice whether home or inpatient:) **Diagnosis:** haematological cancer -; **Time period:** survival >6 months +; **Age:** >=80 - ; **Sex:** 0 ; **Other:** born in UK or Europe +; rural residence -
Costantini, Toscani, Gallucci, Brunelli, Miccinesi, Tamburini, Paci et al (1999)	Random sample of 589 patients from all 2667 eligible patients admitted to 58 Italian palliative care units January-June 1995. Eligible patients were age 18 or above, required palliative care and resident in unit catchment area.	Prospective data collected by participating units. Chi-square and Kaplan-Meier survival analysis	**Time period:** survival from admission + ; **Sex:** female -

APPENDIX 2: Observational study results

APPENDIX 2

Table 2.1: Comparison of admitted and non-admitted HAH patients; Demographic and clinical data

	HAH not admitted n=59	HAH admitted n=62	Significance levels
CAUSE OF DEATH:	**n (%)**	**n (%)**	
Cancer only cause	48 (81.4)	51 (82.3)	
One or more other causes recorded alongside cancer	11 (18.6)	11 (17.7)	X^2=0.000, d.f.=1, p=1.000
SURVIVAL:	**Median (i.q.r.)**	**Median (i.q.r.)**	Log Rank statistic=0.26.
Days between diagnosis and death	248 (863)	273 (749)	d.f.=1, p=0.609
Diagnosis within a month of death:	**n (%)**	**n (%)**	
Yes	5 (8.5)	2 (3.2)	
No	54 (91.5)	60 (96.8)	X^2=0.717, d.f.=1, p=0.397
DIAGNOSIS:[1]	**n (%)**	**n (%)**	
Breast	6 (10.2)	7 (11.3)	
Gastro-intestinal	13 (22.0)	17 (27.4)	
Genito-urinary	9 (15.3)	7 (11.3)	
Haematologial cancers	4 (6.8)	3 (4.8)	
Respiratory	9 (15.3)	10 (16.1)	
Other	18 (30.5)	18 (29.0)	X^2=0.982, d.f.=5, p=0.964
AGE:	**Mean (s.d.)**	**Mean (s.d.)**	
	70.1 (15.3)	71.0 (12.4)	t=0.343, d.f.=119, p=0.732
SEX:	**n (%)**	**n (%)**	
Females	32 (54.2)	36 (58.1)	
Males	27 (45.8)	26 (41.9)	X^2=0.058, d.f.=1, p=0.810
MARRIED:	**n (%)**	**n (%)**	
Females-Yes	11 (40.7)	19 (65.5)	
No	16 (59.3)	10 (34.5)	X^2=2.527, d.f.=1, p=0.112
Males –Yes	13 (81.3)	14 (73.7)	
No	3 (18.8)	5 (26.3)	X^2=0.016, d.f.=1, p=0.899
SOCIOECONOMIC AREA:[1]	**Median (i.q.r)**	**Median (i.q.r.)**	
Jarman UPA score.	-4.14 (22.05)	-0.96 (17.74)	Z=1.377, p=0.168
Townsend index.	-1.17 (4.28)	-1.07 (3.93)	Z=0.827, p=0.927
SOCIAL CLASS:	**n (%)**	**n (%)**	
I	6 (10.2)	7 (12.3)	
II	19 (32.2)	17 (29.8)	
IIIN	5 (8.5)	7 (12.3)	
IIIM	14 (23.7)	16 (28.1)	
IV-V	15 (25.4)	10 (17.5)	X^2=1.621, d.f.=4, p=0.805

[1] Due to the reduced numbers involved in this subset analysis, some categories were collapsed so as not to violate the assumptions of the X^2 test (Siegel an Castellan, 1991): CNS and head/neck cancer and "other" cancer; occupational class categories IV and V.

APPENDIX 2

Table 2.2: Comparison of admitted and non-admitted HAH patients; GP and district nurse characteristics; n recorded in the table

	HAH not admitted	HAH admitted	Significance levels
GP LIST SIZES	**Mean (s.d.)**	**Mean (s.d.)**	
	(n=56)	(n=52)	
GP total list size	1864 (490)	1734 (507)	Z=1.417, p=0.156
List size aged 65-74	168 (82)	155 (82)	Z=0.815, p=0.415
List size aged > 75	153 (73)	144 (74)	Z=0.489, p=0.625
Rural patients	0.35 (0.59)	0.32 (0.62)	Z=0.643, p=0.520
GP PRACTICE CHARACTERISTICS	**Median (i.q.r.)**	**Median (i.q.r.)**	
	(n=59)	(n=62)	
Number of partners:	5 (2)	5 (2)	Z=0.129, p=0.898
Training practice:	***n* (%)**	***n* (%)**	
Yes	34 (57.6)	33 (55.0)	
No	25 (42.4)	27 (45.0)	X^2=0.011, d.f.=1, p=0.917
Fundholding practice:	**n (%)**	**n (%)**	
Yes	7 (11.9)	13 (21.7)	
No	52 (88.1)	47 (78.3)	X^2=1.403, d.f.=1, p=0.236
DISTRICT NURSE TEAM			
Based at surgery:	**n (%)**	**n (%)**	
Yes	40 (67.8)	38 (65.5)	
No	19 (32.8)	20 (34.5)	X^2=0.004, d.f.=1, p=0.948
Team size	**Median (i.q.r.)**	**Median (i.q.r.)**	
	(n=57)	(n=56)	
	4 (2)	4 (2)	Z=0.124, p=0.902
DN sisters and RGNs in team:	**Median (i.q.r.)**	**Median (i.q.r.)**	
	(n=59)	(n=58)	
	2 (2)	2 (2)	Z=0.106, p=0.916

Table 2.3: Comparison of admitted and *non-admitted* HAH patients; Cancer Registry records of contact with hospital.

	HAH not admitted n=59	HAH admitted n=62	Significance level
In contact with hospital:	**n (%)**	**n (%)**	
Yes	58 (98.3)	57 (91.9)	
No	1 (1.7)	5 (8.1)	X^2=1.426, d.f.=1, p=0.232
In contact with oncology department:	**n (%)**	**n (%)**	
Yes	33 (55.9)	36 (58.1)	
No	26 (44.1)	26 (41.9)	X^2=0.003, d.f.=1, p=0.958

APPENDIX 2

Table 2.4: Comparison of admitted and non-admitted HAH patients; Number (percentage) of patients who received a service in their last year of life

	HAH not admitted	HAH admitted	Significance level
Addenbrooke's inpatient	48 (81.4)	45 (72.6)	X^2=0.862, d.f.=1, p=0.353
Addenbrooke's daycase	12 (20.3)	14 (22.6)	X^2=0.006, d.f.=1, p=0.937
Addenbrooke's outpatient appt[1]	33 (55.9)	40 (64.5)	X^2=0.607, d.f.=1, p=0.436
Hospice care	30 (50.8)	16 (25.8)	X^2=7.017, d.f.=1, p=0.008
Other Lifespan inpatient	2 (3.4)	2 (3.2)	X^2=0.000, d.f.=1, p=1.000
Papworth	5 (8.5)	5 (8.1)	X^2=0.000, d.f.=1, p=1.000
District nursing	53 (89.8)	58 (93.5)	X^2=0.170, d.f.=1, p=0.680
Night nursing	12 (20.3)	19 (30.6)	X^2=1.188, d.f.=1, p=0.276
Macmillan nursing	22 (37.3)	23 (37.1)	X^2=0.000, d.f.=1, p=1.000
Marie Curie	29 (49.2)	47 (75.8)	X^2=8.089, d.f.=1, p=0.004
Other Lifespan primary care	10 (16.9)	10 (16.1)	X^2=0.000, d.f.=1, p=1.000
Flexible care	7 (11.9)	16 (25.8)	X^2=2.965, d.f.=1, p=0.085

Table 2.5: Comparison of admitted and non-admitted HAH patients; Amount of input per patient in the last year of life for those patients who had a service. Median (interquartile range). Mann Whitney U tests used for comparison

	HAH not admitted	n	HAH admitted	n	Significance level
Addenbrooke's inpatient days	21.5 (19.5)	48	18 (27.5)	45	Z=0.023, p=0.982
Addenbrooke's daycase appointment	1.5 (2.75)	12	2.5 (6.25)	14	Z=0.661, p=0.509
Addenbrooke's outpatient appointments[1]	2 (2)	33	2 (2)	40	Z=0.442, p=0.658
Hospice care	14 (10.5)	30	10.5 (35.3)	16	Z=0.312, p=0.755
Other Lifespan inpatient days	56.5 (.)	2	10 (.)	2	Z=1.549, p=0.121
Papworth inpatient days	23 (24.5)	5	5 (30.5)	5	Z=0.731, p=0.465
District nursing hours	15.1 (16.8)	53	25.5 (29.8)	58	Z=3.046, p=0.002
Night nursing hours	2.4 (3.8)	12	3.8 (4.1)	19	Z=1.075, p=0.282
Macmillan nursing hours	2.5 (6.9)	22	1.8 (3.3)	23	Z=0.602, p=0.547
Marie Curie nursing hours	18 (38.9)	29	33 (50.5)	47	Z=1.693, p=0.090
Other Lifespan primary care hours	2.0 (1.8)	10	0.9 (2.0)	10	Z=0.795, p=0.427
Flexible care hours	12 (22)	7	4.5 (14.1)	7	Z=1.138, p=0.255

APPENDIX 2

Table 2.6: Comparison of admitted and non-admitted HAH patients; onset of care for those patients who received a service. Median (interquartile range)

	HAH not admitted	n	HAH admitted	n	Significance level
Addenbrooke's inpatient care	144.5 (153.3)	48	135 (169.5)	45	Z=0.404, p=0.686
Addenbrooke's daycase appointments	179.5 (185.8)	12	190 (135,233)	14	Z=0.103, p=0.918
Hospice care	17.5 (15.5)	30	36.5 (134.5)	16	Z=1.455, p=0.146
Other Lifespan inpatient care	70 (.)	2	17.5 (.)	2	Z=1.549, p=0.121
Papworth inpatient care	225 (192.5)	5	244 (251)	5	Z=0.522, p=0.602
District nursing	116 (140.5)	53	74.5 (151.3)	58	Z=1.104, p=0.270
Night nursing	14 (55)	12	9 (13)	19	Z=0.081, p=0.935
Macmillan nursing	79.5 (170)	22	86 (98)	23	Z=0.341, p=0.733
Marie Curie nursing	16 (32)	29	21 (44)	47	Z=0.551, p=0.582
Other Lifespan primary care	31 (84.8)	10	32.5 (116.8)	10	Z=0.643, p=0.520
Flexible care	15 (147)	7	20 (41.3)	16	Z=0.332, p=0.738

APPENDIX 2

Table 2.7: Categorisation of variables for logistic regression; age, Jarman index, number of GP practice partners and GP list size. Median (quartiles), number of patients for each quartile

	Median (quartiles)	<=1st quartile	>1st,<=2nd quartile	>2nd, <=3rd quartile	>3rd quartile
Age	75.29 (67.38, 81.95)	81	79	87	80
Jarman index	-0.94 (-8.12, 11.89)	82	92	72	81
No of GP partners	5 (4,6)	111	98	69	34
GP list size	1950 (1641, 2099)	67	71	66	65

Table 2.8: Categorisation of variables for logistic regression; onset of care (days before death). Median for patients receiving care, number of patients for each variable category (Late onset: value at or below median. Early onset: value above median).

	Median onset for patients receiving care	Input/ early onset	Input/ late onset	No input/ referral	No input
Hospital at home	7	27	34	60	206
Hospice care	16	44	46	N/A	237
Papworth inpatient input	123.5	16	16	N/A	295
Lifespan inpatient input	41.5	7	7	N/A	313
Night nursing	10	24	25	N/A	278
Macmillan nursing	86	35	37	N/A	255
Marie Cure nursing	20	45	48	N/A	234
Flexible care	27	15	15	N/A	297
Other Lifespan primary care	37	18	19	N/A	290
District nursing[1]	100.5	118	118	N/A	91

[1] Further subdivided for analysis

Table 2.9: Categorisation of variables for logistic regression; amount of care (inpatient care days, nursing care hours). Median for patients receiving care, number of patients for each variable category (Low amount: value at or below median. High amount: value above median)

	Median amount for patients receiving care	Input/ Low amount	Input/ high amount	No input/ referral	No input (Reference category)
Hospital at home	31	31	30	60	206
Hospice care	12.5	45	45	N/A	237
Papworth inpatient input	13.5	16	16	N/A	295
Lifespan inpatient input	18.5	7	7	N/A	313
Night nursing	2.9	25	24	N/A	278
Macmillan nursing	2.2	36	36	N/A	255
Marie Cure nursing	27	47	46	N/A	234
Flexible care	11	15	15	N/A	297
Other Lifespan primary care	1.25	19	18	N/A	290
District nursing[1]	12.4	119	117	N/A	91

[1] Further subdivided for analysis

APPENDIX 2

Table 2.10: Categorisation of variables for logistic regression; district nursing, number of patients in each category when crosstabulating onset and amount for district nursing care.

	ONSET		
AMOUNT	**Input/ Late onset**	**Input/ Early onset**	**No input (Reference category)**
No input	(0)	(0)	91
Input/ Amount low	72	47	(0)
Input/ Amount high	46	71	(0)

APPENDIX 2

Table 2.11: Logistic regression analysis; demographic, clinical and service input variables. Service variables subdivided on amount of care. Variables coefficients which differ significantly at p<0.05 share the same superscript.

	Coefficient	SE	p	Odds Ratio (95% CI)
Hospice care			<0.0001	
Input, high amount	-2.398	0.505	<0.0001	0.091 (0.034, 0.245)
Input, low amount	-2.248	0.505	<0.0001	0.106 (0.039, 0.284)
No input	0			1
District nursing care			<0.0001	
Input, amount high, onset late	2.210^{AB}	0.501	<0.0001	9.116 (3.413, 24.346)
Input, amount high, onset early	1.189^{A}	0.446	0.0077	3.285 (1.370, 7.877)
Input, amount low, onset late	0.725^{BC}	0.372	0.0515	2.065 (0.995, 4.284)
Input, amount low, onset early	-0.518^{C}	0.517	0.3165	0.596 (0.217, 1.641)
No input	0			1
Marie Curie care			<0.0001	
Input, high amount	2.042	0.520	0.0001	7.702 (2.778, 21.356)
Input, low amount	1.604	0.428	0.0002	4.975 (2.149, 11.511)
No input	0			1
Constant	-0.723	0.240	0.0026	

N=327, 75.84% of cases correctly classified; Model X^2=114.004, d.f.=8, p<0.0001; Number of outliers with SRESID of 2 or more=6; Residual X^2 for variables not in the equation=35.527, d.f.=28, p=0.1550; Goodness of Fit=311.010.

Table 2.12: HAH input, demographic, clinical and service input variable analysis. Service variables subdivided on amount of care. Simple contrasts. Variable subdivisions for which coefficients differ significantly share the same superscript.

	Coefficient	SE	P	Odds Ratio (95% CI)
Hospital at home care			<0.0001	
Input, amount high	$3.870^{?}$	0.845	<0.0001	47.939 (9.148, 251.220)
Input, amount low	2.145	0.548	0.0001	8.540 (2.920, 24.973)
Referral only, no input	$1.530^{?}$	0.401	0.0001	4.618 (2.103, 10.141)
No input, no referral	0			1
Hospice care			<0.0001	
Input, high amount	-2.275	0.531	<0.0001	0.103 (0.036, 0.291)
Input, low amount	-2.626	0.548	<0.0001	0.072 (0.025, 0.212)
No input	0			1
District nursing care			0.0003	
Input, amount high, onset late	$1.882^{?}$	0.543	0.0005	6.567 (2.268, 19.014)
Input, amount high, onset early	1.251	0.444	0.0048	3.495 (1.465, 8.337)
Input, amount low, onset late	$0.648^{A?}$	0.390	0.0965	1.911 (0.890, 4.101)
Input, amount low, onset early	-0.652^{A}	0.535	0.2233	0.521 (0.183, 1.488)
No input	0			1
Constant	-0.394	0.286	0.1677	

n=327; 78.29% of cases correctly classified; Model X^2=139.686, d.f.=9, p<0.0001; Number of outliers with SRESID of 2 or more=6; Residual X^2 for variables not in the equation=36.486, d.f.=30, p=0.1926; Goodness of Fit=291.079.

APPENDIX 3: Randomised controlled trial

Table 3.1: Next of kin; n recorded in table.

	Control group	HAH group
Husband	15 (34.9)	46 (24.7)
Wife	17 (39.5)	70 (37.6)
Son	3 (7.0)	15 (8.1)
Daughter	4 (9.3)	33 (17.7)
Other[1]	3 (7.0)	16 (8.6)
None recorded	1 (2.3)	6 (3.2)

[1]Other: siblings, daughters in law, nieces, grandchildren, parents (12 cases) and friends, a landlady and a lodger (7 cases).

Table 3.2: Diagnosis as recorded on HAH records

	Control group	HAH group
Cancer		
Breast	4 (9.3)	14 (7.5)
CNS	0 (0.0)	8 (4.3)
Gastrointestinal	5 (11.6)	43 (23.1)
Genitourinary	13 (30.2)	32 (17.2)
Head and neck	0 (0.0)	5 (2.7)
Haematological cancers	1 (2.3)	10 (5.4)
Lung	7 (16.3)	16 (8.6)
Cancer other	7 (16.3)	31 (16.7)
Cancer total	37 (86.0)	159 (85.5)
Non-cancer		
Circulatory disease	4 (9.3)	11 (5.9)
AIDS	0 (0.0)	5 (2.7)
Nervous system	0 (0.0)	5 (2.7)
Pneumonia	2 (4.7)	1 (0.5)
Non-cancer other	0 (0.0)	5 (2.7)
Non-cancer total	6 (14.0)	27 (14.5)

"Cancer other" are ill defined cancer, melanoma, mesothelioma, and cancer of the thyroid. pancreas, bile duct and liver (not metastases). Circulatory disease includes cerebrovascular accident (3 cases). Diseases of the nervous system include motor neurone disease and Parkinsons disease. "Other" non-cancer are diseases of the blood forming organs, digestive or metabolic system and renal failure.

APPENDIX 4: Analysis of actual HAH treatment and place of death

APPENDIX 4

Table 4.1: Diagnosis by admitted and non-admitted HAH patients.

DIAGNOSIS	HAH not admitted	HAH admitted
Cancer	**N (%)**	**N (%)**
Breast	4 (5.5)	10 (8.8)
CNS	3 (4.1)	5 (4.4)
Gastrointestinal	16 (21.9)	27 (23.9)
Genitourinary	9 (12.3)	23 (20.4)
Head and neck	2 (2.7)	3 (2.7)
Haematological cancers	6 (8.2)	4 (3.5)
Lung	8 (11.0)	8 (7.1)
Cancer other	15 (20.5)	16 (14.2)
Cancer total	63 (86.2)	96 (85.0)
Non-cancer		
Circulatory disease	5 (6.8)	6 (5.3)
AIDS	2 (2.7)	3 (2.7)
Nervous system	2 (2.7)	3 (2.7)
Pneumonia	0 (0.0)	1 (0.9)
Non-cancer other	1 (1.4)	4 (3.5)
Non-cancer total	10 (13.6)	17 (15.1)

"Cancer other" are ill defined cancer, melanoma, mesothelioma, and cancer of the thyroid. pancreas, bile duct and liver (not metastases). Circulatory disease includes cerebrovascular accident (3 cases). Diseases of the nervous system include motor neurone disease and Parkinsons disease. "Other" non-cancer are diseases of the blood forming organs, digestive or metabolic system and renal failure.

Table 4.2: Social Class by admitted and non-admitted HAH patients

SOCIAL CLASS	HAH not admitted	HAH admitted
	n (%)	**n (%)**
I	12 (16.7)	10 (9.5)
II	18 (25.0)	22 (21.0)
IIIN	6 (8.3)	15 (14.3)
IIIM	20 (27.8)	26 (24.8)
IV	11 (15.3)	29 (27.6)
IV and V	5 (6.9))	3 (2.9)

APPENDIX 4

Table 4.3: Categorisation of variables for logistic regression; survival after referral, survival after diagnosis and GP list size. Median (quartile values) and number of patients in each quartile

	Median (quartiles)	<=1st quartile	>1st, <=2nd quartile	>2nd, <=3rd quartile	>3rd quartile
Survival after referral (days)	11 (4, 32)	64	52	56	57
Survival after diagnosis (days)	321.5 (110.75, 963.75)	47	48	48	47
GP list size	1881 (1542, 2094.25)	55	54	50	53

Table 4.4: Categorisation of variables for logistic regression; onset of care (days before death) Median value for patients receiving care. *Number of patients in each coding category.*

	Median value for patients receiving care	No input	Input/ value at or below median	Input/ Value above median
Hospital at Home	12	113	61	55
Addenbrooke's daycase	202	181	24	24
Hospice care	45	150	40	39
Papworth inpatient care	148	213	8	8
District nursing	154	28	101	100
Night nursing	11.5	177	26	26
Macmillan nursing	81	161	34	34
Marie Curie nursing	27	110	61	58
Other Lifespan primary care	70	175	27	27
Flexible Care	44	184	24	21

Table 4.5: Categorisation of variables for logistic regression; amount of care. Median (patients receiving input only). Number of patients in each coding category

	Median value for patients receiving care	No input	Input/ value at or below median	Input/ Value above median
HAH hours	51.05	113	58	58
Addenbrooke's daycase appt.	1.50	181	24	24
Hospice days	14	150	40	39
Papworth inpatient days	8	213	8	8
District nursing hours	20.58	28	101	100
Night nursing	3.0833	177	26	26
Macmillan hours	2.08	161	34	34
Marie Curie hours	36.00	110	61	58
Other Lifespan primary care	1.5	185	30	24
Flexible Care	12	184	23	22

APPENDIX 4

Table 4.6: Categorisation of variables for logistic regression; district nursing, number of patients in each category when crosstabulating onset and amount for district nursing care.

	ONSET		
AMOUNT	**Input/ Late onset**	**Input/ Early onset**	**No input (Reference category)**
No input	(0)	(0)	28
Input/ Amount low	63	38	(0)
Input/ Amount high	38	62	(0)

APPENDIX 4

Table 4.7: Logistic regression analysis. Demographic, clinical and service input variable analysis of likelihood of home death. Service variables subdivided on amount of care. Simple contrasts. Variable coefficients which differ significantly at p<0.05 share the same superscript.

	Coefficient	SE	p	Odds Ratio (95% CI)
Survival from HAH referral			0.0001	
<= 4 days	2.509[A]	0.573	<0.0001	12.291 (4.002, 37.752)
>4 and <=11 days	0.986[A]	0.532	0.0638	2.679 (0.945, 7.598)
>11 and <=32 days	1.637	0.537	0.0023	5.140 (1.794, 14.725)
>32 days	0			1
Hospice care			0.0002	
Input, high amount	-1.870	0.545	0.0006	0.154 (0.053, 0.449)
Input, low amount	-1.722	0.500	0.0006	0.179 (0.067, 0.476)
No input	0			1
Night nursing care			0.0009	
Input, high amount	2.605	0.802	0.0012	13.529 (2.811, 65.119)
Input, low amount	1.603	0.795	0.0438	4.966 (1.046, 23.582)
No input	0			1
Marie Curie care			<0.0001	
Input, high amount	2.889[A]	0.578	<0.0001	17.981 (5.796, 55.784)
Input, low amount	1.427[A]	0.453	0.0016	4.168 (1.715, 10.128)
No input	0			1
Macmillan nursing care			0.0452	
Input, high amount	1.016[A]	0.579	0.0793	2.763 (0.888, 8.594)
Input, low amount	-0.758[A]	0.516	0.1416	0.469 (0.171, 1.288)
No input	0			1
Constant	1.715	0.409	<0.0001	

n=229, 79.48% cases correctly classified (87.9% of home deaths and 63.8% of inpatient deaths); Model X^2=97.431, d.f. =11, p<0.0001; Number of outliers with SRESID of 2 or more =5; Residual X^2 for variables not in the equation =18.117 with, d.f .=17, p=0.3815; Goodness of Fit=212.262.

APPENDIX 4

Table 4.8: *Logistic regression analysis. HAH, clinical and service input variable analysis of likelihood of home death. Service variables subdivided on amount of care. Simple contrasts. Variable coefficients differ significantly at p<0.05 share the same superscript.*

	Coefficient	SE	p	Odds Ratio (95% CI)
Hospital at home care			0.0113	
Input, high amount	1.596	0.536	0.0029	4.932 (1.724, 14.110)
Input, low amount	0.652	0.476	0.1709	1.919 (0.755, 4.875)
No input	0			1
Survival from HAH referral			<0.0001	
<= 4 days	2.836[A]	0.606	<0.0001	17.047 (5.198, 55.908)
>4 and <=11 days	1.239[A]	0.559	0.0268	3.451 (1.153, 10.330)
>11 and <=32 days	1.779	0.565	0.0016	5.924 (1.958, 17.921)
>32 days	0			1
Hospice care			0.0001	
Input, high amount	-2.103	0.585	0.0003	0.122 (0.039, 0.384)
Input, low amount	-1.779	0.520	0.0006	0.169 (0.061, 0.468)
No input	0			1
Night nursing care			0.0032	
Input, high amount	2.437	0.812	0.0027	11.440 (2.330, 56.155)
Input, low amount	1.431	0.814	0.0787	4.184 (0.849, 20.636)
No input	0			1
Marie Curie care			0.0003	
Input, high amount	2.374[A]	0.604	0.0001	10.736 (3.288, 35.053)
Input, low amount	1.175[A]	0.479	0.0141	3.238 (1.267, 8.275)
No input	0			1
Macmillan nursing care			0.0501	
Input, high amount	1.112[A]	0.594	0.0615	3.039 (0.948, 9.742)
Input, low amount	-0.659[A]	0.519	0.2047	0.518 (0.187, 1.432)
No input	0			1
Constant	1.739	0.417	<0.0001	

n=229, 80.79% cases correctly classified; Model X^2=107.221, d.f. =13, p=0.0000; Number of outliers with SRESID of 2 or more =7; Residual X^2 for variables not in the equation =15.650 with, d.f .=17, p=0.5488; Goodness of Fit=201.816